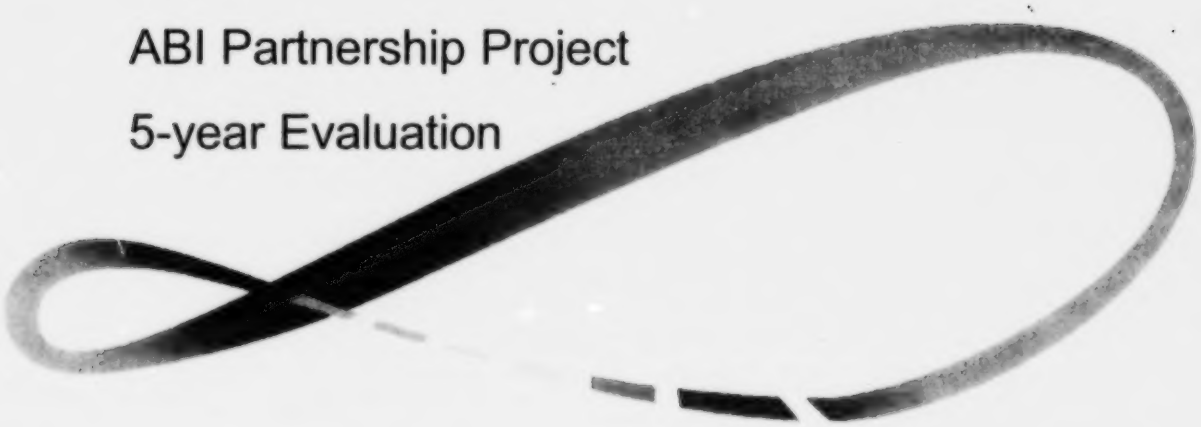
Saskatchewan Health

SGI

Summary of Key Findings:

ABI Partnership Project

5-year Evaluation



May 2004

ACKNOWLEDGEMENTS

The information contained in the report reflects the work of many people. We would like to extend our thanks to the clients, family members, service providers and key informants who were involved in the evaluation of the ABI Partnership Project. We also wish to acknowledge the contributions of: members of the ABI Advisory Group; Jon Schubert, Independent Consultant, for conducting the cost benefit analysis; Mark Sagan, Clinical Research and Development Department of Wascana Rehabilitation Centre, for the report on the Wascana Client-Centered Care Survey; and University of Regina Professor Donald Sharpe for his assistance in the analysis of our client outcome data.

The evaluation has been an ambitious undertaking for all those involved. We believe the report demonstrates the benefit of the service continuum that is the ABI Partnership Project. It has yielded a wealth of information about these services and will help us to set future directions and priorities for delivering community-based services in Saskatchewan for individuals with ABI, their families and communities.

Michele Cairns
Provincial ABI Coordinator

Traci Schmekel
Evaluation Assistant

Kelly Froehlich
Provincial ABI Education and Prevention Coordinator

Table of Contents

Introduction 1

Evaluation Methodology 3

Data Collection 3

Table 1: Data Collection Tools 3

Results Summary 4

Demographics 6

Table 2: Client Demographics at Intake from ABIIS Client Registration 7

Program Outcomes 8

The Model 10

Figure 1: Clients Seen By Funded Programs and Outreach Teams 16

Figure 2: From Referral Source by each Category 16

Figure 3: ABI Partnership Project Service Continuum 22

Figure 4: All Programs – Client Service Events 23

Figure 5: All Programs – Family Service Events 24

Table 3: 2002 Funding by program component 25

Figure 6: Service Provider Survey – Quantitative Results 26

Figure 7: PIR Survey – Quantitative Results 26

Client Outcomes 27

Figure 8: Saskatchewan Outcomes Questionnaire (SOQ)- Community Integration – Wave 1 Responses 28

Figure 9: Saskatchewan Outcomes Questionnaire – Wave 1-3 28

Table 4: Case Study, Successful Client Goal Attainment 29

Table 5: Client Outcomes Questionnaire Package Wave One 30

Table 6: Wave One and Two Comparisons 32

Education and Prevention 33

Figure 10: Community Service Events 34

Figure 11: Brain Walk Results 36

Recommendations 40

Appendices 44

Appendix A: Cause of Injury
Appendix B: Map Strategy for Services
Appendix C: ABI Service Provider Survey
Appendix D: ABI Service Provider Survey – Qualitative Results
Appendix E: PIR Survey
Appendix F: PIR Survey – Qualitative Results
Appendix G: SOQ Community Integration Questions
Appendix H: Reductions in ABI
Figure 1: ABI Hospital Separations
Figure 2: Proportion of ABI Separations

EXECUTIVE SUMMARY

Since its inception in January 1996, SGI has provided $27.15M in funding to establish a "*comprehensive, integrated system of supports, resources and services that will enhance the rehabilitation outcomes and improve the quality of life for individuals with acquired brain injuries and their families.*"[1] This system of services is now known as the ABI Partnership Project.

Over the past eight years the Partnership has served over 1900 clients.

This evaluation report focuses on client and program outcomes. Building on the process evaluation work conducted during the pilot phase (1998), second-phase process evaluations were conducted at the site-level, with all funded agencies required to submit evaluation reports in April 2001. This report builds upon the work in these evaluation phases, covering the time period April 1, 2001 to March 31, 2003. Site-level reports, Acquired Brain Injury Information System (ABIIS) data, service provider surveys, and Advisory Group feedback have all informed this process.

A client profile shows that 66% of Partnership clients are male, 36% were injured in a motor vehicle collision, 84% live independently or supported in their own or family home and 44% are either unemployed or unemployable.

The evaluation shows that the ABI Partnership Project is an effective service delivery model; it strives toward continuous quality improvement in providing client-centred care.

A cost benefit analysis suggests that the current global funding arrangement continues to make sense. It shows that SGI "breaks even" on its investment in the Partnership and that greater benefits accrue to the Province, overall, as a result of Partnership services.

A review of current literature suggests that the service components of the Partnership are well suited to meet the varying needs of individuals with moderate to severe acquired brain injury.

The Partnership has grown into a strong continuum of community-based services. It has grown from 30 programs funded under the Pilot Phase (1996-1998) to 43 programs currently funded in 2003.

The ABI Partnership is seen as a valuable community resource. Referral patterns indicate that the community is aware of and is referring to the Partnership across the service continuum.

Advisory Group and service provider feedback indicates that the Partnership has addressed gaps and that its service delivery is "on track" as intended in the *ABI Strategy for Services*.
The Partnership has created strong community capacity to address ABI. In-kind contributions from funded programs amount to $1.194M annually.

---

[1] **Source:** Acquired Brain Injury Working Group. September 1995. *Acquired Brain Injury: A Strategy for Services.*

Through regular offering of educational opportunities and the tenure of Partnership staff, Saskatchewan expertise has increased to address ABI.

Client Outcome data indicates that the Partnership is reaching its primary goals and objectives. Clients are generally satisfied with Partnership services delivered across the province. They are maintaining their functional gains in terms of physical, social and emotional functioning at one-year in the community, and case studies illustrate how Partnership services are assisting clients with successful goal attainment – helping them to reintegrate into community life with improved quality of life.

INTRODUCTION

In 1995, Saskatchewan Government Insurance (SGI) introduced the Personal Injury Protection Plan (now referred to as No Fault) substantially increasing benefits for rehabilitation services. Policyholders were no longer eligible to claim for pain and suffering, but accident expenses, income replacement and rehabilitation. Benefits for rehabilitation services were increased from $10,000 to $500,000 regardless of fault. Saskatchewan Health is a member of the SGI Rehabilitation Advisory Board and assisted with the implementation of No Fault insurance.

As a result of stakeholder feedback obtained through a variety of forums, surveys, and reports submitted to Health since 1992, recommendations from SGI's Rehabilitation Advisory Board, and based on a service framework developed by the Acquired Brain Injury Working Group, **SGI and Saskatchewan Health developed a unique partnership in late 1994 to establish a** *"comprehensive, integrated system of supports, resources and services that will enhance the rehabilitation outcomes and improve the quality of life for individuals with acquired brain injuries and their families."* [1]

In January 1996 a three-year pilot project was funded with a commitment from SGI of $9.3 million over three years from 1996 to 1998. Saskatchewan Health provided management and coordination of the project and a Provincial Advisory Group was formed to provide ongoing consultation.

After completing a comprehensive evaluation of the implementation phase of the pilot project, the Board of Directors of SGI approved a five-year extension of funding of the ABI initiative ($17.85 million from 1999 to 2003). Now known as the ABI Partnership Project the partnership consists of 36 community-based and 7 education and prevention programs. SGI has provided the Partnership with a total of $27.15 million in funding to date.

Although services that were put in place to address ABI were based on best practices reported in a number of different sectors, no single program or system of services existed elsewhere in Canada or the United States like the ABI Partnership Project prior to its establishment. The ABI Advisory Group, SGI and Saskatchewan Health have made an ongoing commitment to survivors, families, service providers and funders to evaluate the effectiveness of this unique program in supporting individuals and their families to live in the community with an improved quality of life.

---

[1] **Source:** Acquired Brain Injury Working Group. September 1995. *Acquired Brain Injury: A Strategy for Services.*

The outcome phase of the evaluation is intended to record the progress towards addressing the following:

1) Accountability to the funding agency, service providers, survivors and their families;
2) Building capacity to address ABI;
3) Reducing brain injuries;
4) Increasing service coordination and integration;
5) Better integrating clients in their communities;
6) Service delivery that is contributing to improved quality of life for survivors of ABI; and
7) Determining future needs and gaps in the service system as identified by survivors, their families and service providers.

Evaluation Questions

General

1. Are programs demonstrating accountability to our program funder, service providers, individuals with ABI, their families and communities?
2. Is the Partnership meeting the needs of individuals with ABI and their families?
3. Are programs delivering services as intended?
4. Is there increased coordination and integration of ABI services?
5. Has quality of life and community integration increased for individuals with ABI and their families?

Prevention and Education

1. Has awareness of the community increased toward the prevention of ABI?
2. Has knowledge regarding ABI increased for individuals with ABI, their families, service providers and communities?

Evaluation Limitations

Despite the best intentions for a complete evaluation, it must be noted that there are several limitations that may affect certain aspects of it. The evaluation does not utilize all evaluation methods, nor does it present an exhaustive analysis of all information sources that have informed this process; in the interests of summation, not all information sources were included in the final report. A listing of limitations is detailed below:

- Researcher Bias – evaluation overseen and report written by permanent staff who project manage the Partnership Project;
- Data integrity of summary statistics from the Acquired Brain Injury Information System (ABIIS) is compromised because of inconsistent data entry practices by front-line staff utilizing the ABIIS;
- The lack of a control group for the purposes of analysing and comparing client outcome data;
- Survey instruments were not used to the same degree by programs across the service continuum;

- Methods Matching – Mail-out Questionnaires may not be the most valid means of soliciting client self-report feedback for a target population with severe cognitive impairments – concern that a non-representative sample of clients (i.e., those with the highest levels of functioning) were capable and motivated to respond; and
- Statistically significant results were not evidenced on client outcome questionnaire data because of lack of longitudinal data and small sample sizes

EVALUATION METHODOLOGY

In 1998 a process evaluation was conducted to look at the implementation of the pilot project. This process evaluation utilized both qualitative and quantitative information. An external evaluator conducted the qualitative portion of the evaluation focusing on client and family satisfaction with services. High satisfaction with services was found at that time and action was taken on recommendations that resulted from this process evaluation.

This current evaluation focuses on client and program outcomes. Building on the process evaluation work conducted during the pilot phase (1998), second-phase process evaluations were conducted at the site-level, with all funded agencies required to submit evaluation reports in April 2001. This report details the results of a follow-up site-level outcome evaluation process that has been conducted covering the time period April 1, 2001 to March 31, 2003 upon which demographic data from the Acquired Brain Injury Information System (ABIIS) was utilized. An evaluation workshop was held in October 2001 to assist programs with the development of logic models and evaluation work plans. These documents along with an evaluation report outline provided the conceptual framework upon which to organize site-level evaluation report-writing. All site-level program evaluations were received and their results are included in this analysis.

For this outcome evaluation process a combination of quantitative and qualitative data collection tools were utilized. They include:

Table 1: Data Collection Tools

(ABIIS) – aggregate-level data; site-level reports; Wascana Client-Centered Care Survey (WCCS-R) results; SGI Personal Injury Representatives' (PIR) survey; ABI Partnership Project service provider survey; ABI Advisory Group Focus Day; Cost-Benefit Analysis report; secondary (including Strategy and journal articles) literature review; and a variety of site-level data collection tools [e.g., ABIIS (38 programs), Employer Questionnaire, Staff Questionnaire, Education feedback forms, Referral tracking, Family Questionnaire, Partner Service Provider Questionnaire, Case Studies (23 programs), Chart Review/Client Goal Attainment, Client Questionnaires, and Interviews].

RESULTS SUMMARY

A summary of evaluation results and the evaluation area they address is detailed below.

- **Program/Client Outcomes** - ABIIS - demographic information and service event profiles showing scope of service, service utilization, and referral patterns.

- **Program/Client Outcomes** - ABI Partnership Project Service Provider Survey - distributed to all funded agencies (approximately 66 staff) in order to identify issues pertaining to program support. On a 5-point likert scale with 1 representing "strongly agree" and 5 representing "strongly disagree", the overall rating regarding provincial support to funded agencies was 1.8.

- **Program Outcomes** - SGI Personal Injury Representative (PIR) Survey - distributed to 11 PIRs in order to identify issues pertaining to coordination of services between the Partnership and SGI. On a 5-point likert scale with 1 representing "strongly agree" and 5 representing "strongly disagree", the overall rating of PIR respondents' perceptions on service coordination was 2.19.

- **Program/Client Outcomes** - Wascana Client-Centered Care Survey - mailed out to 799 registered ABI clients in January 2003 in order to determine client satisfaction with the Partnership. On a 5-point likert scale with 1 representing "highly client-centered care", the Partnership received an overall rating of 2.01 showing that clients are generally satisfied with the services being offered.

- **Client Outcomes** - A Client Outcome Questionnaire package has been administered since February 2002. Analysis was completed on 127 baseline questionnaires and 22 one-year/inactivation questionnaires. The client outcome questionnaire package seeks to determine long-term outcomes for persons with a brain injury who have received services delivered by the Acquired Brain Injury Partnership Project. Wave 1 results of statistical significance are noted by demographic variable. A Wave 1 and 2 comparison was conducted on a sub-sample (n=22) of respondents. The comparative analysis found no significant differences, however the trend points to client maintenance of function across the domains measured. For detailed results see the Client Outcome text and Tables 5 and 6.

- **Client Outcomes -** Case studies demonstrate clients' enhanced quality of life through successful client goal attainment across a number of areas including community integration.

- **Program Outcome** - A literature review was undertaken in order to provide support for the current model of service delivery.

- **Program Accountability** - A cost benefit analysis was prepared to compare the costs of providing services outside of the Partnership. The findings show that based on the 2001 cost of Partnership services (rehabilitation, prevention and education), the health system benefited by between $1.0 and $1.7 million because of SGI's investment. However, when factoring in the savings on insurance claims costs of between $1.2 and $1.5 million that occurred because of the Partnership, the findings suggest a "break-even" scenario for SGI. SGI's investment in 2001 resulted in a return of between a cost of $.5 million and a benefit of $.4 million to SGI. It further suggests an annual financial benefit to the province of between $1.3 and $3.1 million because of SGI's investment in the Partnership.

- **Program Outcome** - An evaluation focus day was held with members of the ABI Advisory Group to gain feedback on service delivery targets established by the *Acquired Brain Injury: A Strategy for Services.* The focus day results show that Advisory Group members feel that the Partnership services are being delivered as intended and suggest areas for future direction and program improvement.

- **Awareness of ABI** - Funding of activities to promote increased awareness of ABI have been one of the mainstays of the Partnership since its inception in 1996. Under the Community Injury Prevention Grant Program there have been 848 projects funded to date for a total of $699,539. **Knowledge of ABI** - Evaluation results for Brain Trust 2001 showed 92% of respondents agreed that the conference met their needs.

- **Knowledge of ABI** - Introduction to ABI Course - 2003 Evaluation results showed that 82% of respondents agreed that the training met their needs and 84% agreed that the material provided was useful.

- **Building Community Partnerships** - In-kind Contributions - analysis of program inputs shows that substantial supports are being provided by in-kind contributions both in terms of financial contributions (building occupancy, staff salary enhancements, transportation, administrative and clinical supervision, administrative support, technical/computer provision and support and accounting services) and human resource contributions. All are inputs that contribute to effective service delivery. Without these inputs many Partnership programs would not be able to offer the scope and quality of services so unique to this service delivery model. These in-kind contributions total $1.194M, annually and include: 1) three-quarters of all programs list building occupancy as an in-kind contribution; 2) $305K is itemized by two of three of the outreach teams in annual in-kind contributions; 3) across the Partnership there are 271 volunteers with total volunteer hours equalling 13,706; 4) matching grants = approximately $292K/annually; 5) Saskatchewan Health has developed and maintains the Acquired Brain Injury Information System (ABIIS) – ABIIS costs to date are approximately 130K.

DEMOGRAPHICS

Target Population

The characteristics of the target population prioritised for service under the Partnership are:

- prioritised within 3 years post-injury.
- a moderate to severe brain injury that is not related to a congenital disorder or a degenerative disease (e.g., Alzheimer's or Multiple Sclerosis).
- individuals who are assessed to show potential for community reintegration (e.g., return to community living, return to work).

A Demographic Profile of the Population Receiving Partnership Services

Based on a discrete client count taken from the Acquired Brain Injury Information System (ABIIS)[2] between the time period of January 1, 2000 to March 31, 2003 the Partnership has provided service to 1903 clients. Consistent with known incidence rates of ABI, 66% (1252) of clients are male. The greatest number of clients served fall within the 18-24 and 30-59 year age brackets. The ABIIS does not presently track age at time of injury. However, research indicates that most brain injuries occur in the 16-25 year age range. The main cause of injury during this evaluation time frame was motor vehicle collision with a total of 36% (678) clients, including 513 who were passengers in vehicles. The remaining 1225 clients sustained their brain injuries through various other traumatic, pathological or chronic means (see Appendix A for a detailed chart on Cause of Injury).

[2] The Acquired Brain Injury Information System was established in January 2000. All Partnership programs (excluding Sherbrooke Community Center and Saskatchewan Institute on Prevention of Handicaps) utilize the ABIIS. The ABIIS provides demographic and service event information on clients with ABI and their families receiving services through one of the Partnership's funded programs.

Table 2: Client Demographics at Intake from ABIIS Client Registration Database
For the period Jan 1, 2000 – March 31, 2003

Program	# of non-discrete clients	Leading Cause of Injury	Gender	Employment	Education	Living Situation	FTEs
All	2797	35% MVC	69% male	-	53.8% secondary	85% independent or supported in own home	58.68
Outreach (3)	1408	41% MVC	66% male	22.7% unemployed; 22.3% student	52% secondary	90% independent or supported in own home	23.96
Program Coordinators (7)	508	40% MVC	63% male	19.2% unemployed; 18.7% retired	62.2% secondary	85% independent or supported in own home	6.1
Residential (2)	113	40% MVC	74% male	45% unemployed; 15.9% unemployable	53% secondary	82.3% independent or supported in own home	9.75
Vocational (4)	243	52% MVC	67% male	44.8% unemployed; 10.7% unemployable	58.8% secondary	87.7% independent or supported in own home	6.67
Independent Living Worker Programs (4)	76	32.9% MVC	65% male	32.8% unemployable; 22.3% retired	46% secondary	90.8% independent or supported in own home	3.2
Crisis (2)	146	43% Other (not TBI); 14% MVC	74% male	47.2% unemployable; 28% unemployed	52% secondary	61.6% independent or supported in own home	1
Children (1)	27	40% MVC	70% male	100% student	66.7% secondary	100% independent or supported in own home	2
Rehabilitation (7)	263	31% stroke; 24% MVC	73% male	24.3% unemployable; 23.6% retired	39.5% secondary	79.1% independent or supported in own home	6

Note: brackets denote number of programs. This table excludes LABIS, Sherbrooke Community Center (both Day Programs), McKerracher, SBIA and all Prevention and Education programs. SAC Regina and Saskatoon Life Enrichment statistics are included under the vocational program component.

PROGRAM OUTCOMES

Evaluation Question 1: Are programs demonstrating accountability to our program funder, service providers, individuals with ABI, their families and communities?

Cost Benefit Analysis

In November 2002, Saskatchewan Health contracted with Jon Schubert, Jon Schubert Consulting, to conduct a cost benefit analysis of the ABI Partnership Project and write a report on the findings. The cost benefit analysis utilizes data from the Acquired Brain Injury Information System (ABIIS) and the Saskatchewan Government Insurance (SGI) claims database to summarize the types of clients and services provided under the Partnership. Using their associated costs, and comparing motor vehicle insurance claims cost savings in Saskatchewan and Manitoba we attempt to answer:

How much would it cost SGI to provide similar services outside of the Partnership to its clients who have sustained a brain injury in a motor vehicle collision?

The findings show that based on the cost of Partnership services (rehabilitation, prevention and education), SGI provided between $1.0 and $1.7 million in additional funds to the health system in 2001. However, when factoring in the savings on claims costs of between $1.2 and $1.5 million that occurred because of the Partnership, the findings suggest a "break-even" scenario for SGI. SGI's investment in 2001 resulted in a return of between a cost of $.5 million and a benefit of $.4 million to SGI. When also taking into account the value of services provided to clients whose brain injuries were for causes other than motor vehicle collisions, the province of Saskatchewan realized a financial benefit of between $1.3 and $3.1 million because of SGI's investment in the Partnership. It is expected the financial benefit determined for 2001 is seen annually.

It is uncertain whether service costs for individuals with ABI would "creep" upward if services were solely provided outside of the Partnership through a fee-for-service model. For this reason, and also because the intangible benefit of the Partnership is largely seen as the infrastructure/network of funded agencies that has been developed to link ABI clients to needed services, these findings support the maintenance of the global funding arrangement (for full report contact the ABI Provincial Office).

Evaluation Question 3: Are programs delivering services as intended?

ABI Advisory Group Evaluation Focus Day

The *Acquired Brain Injury: Strategy for Services* was intended to guide program development in terms of program design. It has served as a report card by which to measure program implementation in terms of the target population addressed and type and quantity of services provided by the ABI Partnership Project.

On March 19, 2003 an Evaluation Focus Day was held with the ABI Advisory Group. The day's goal was to garner feedback regarding the program's current service delivery structure to determine if the Partnership was "on track" in terms of its original intent, what results were apparent as a result of service activity by program component, and to gain advice regarding future program directions.

Discussion of the day divided service components into: 1) Rehabilitation; 2) Crisis Management/Support; 3) Vocational/Avocational/Life Enrichment; 4) Supported Living/Residential Options; 5) Prevention and Education; and 6) Other. Feedback from the day suggests that the Advisory Group feels that the Partnership is indeed on track in terms of its original structure and intent and has accomplished much since its establishment in 1996 to address the needs of individuals with ABI and their families.

Feedback on particular program components included:

Residential Options – there are improved services but not more housing options.

Vocational/Avocational/Life Enrichment – positive outcomes were noted in this area. This service component addresses the needs of clients by promoting independence, providing meaningful activity for clients by helping them to feel productive, providing social support and for families by providing respite.

Program Strengths:

- Creation of Advisory Group
- Increased awareness of ABI
- Provincial networks established
- Continuum of services (varied and dispersed throughout province)
- Partnership looked at as an international model – has been adopted by others
- World Class Conferences (education)
- Community Grant Program (Traffic Safety/Injury Prevention) - [has wide reach in terms of geography and communities of interest (northern/remote, First Nations)]
- Increased capacity in other systems to work with ABI clients
- Brain Walk (prevention/awareness)

Areas for future program improvements:

- More support for rural areas including: crisis management, recreation and leisure
- Education: *to* emergency room and long-term care facility staff *on* best practice models
- Long-term support (some current programming is time-limited)
- Addiction treatment
- Addressing needs of sub-populations 1) recreation and leisure services for seniors; 2) support and programming for children and families is still limited (including respite); and 3) housing for young adults
- Partnerships to be fostered 1) financial; 2) Aboriginal; 3) and appropriate sectors (e.g., Justice)

THE MODEL

Evaluation Question 4: Is there increased coordination and integration of ABI services?

Development of the Saskatchewan Model of Service Delivery

Based on the document *Acquired Brain Injury: A Strategy for Services* developed by the ABI Working Group in 1995, the service delivery structure was conceptualised for the ABI Partnership Project:

Service Delivery Philosophy

- Non-duplication of services
- Built on existing services (i.e., to support the existing service delivery system)
- Continuum of services to address reintegration needs of individuals with ABI and their families
- Individualized and client-centered
- Equal access to service for target population on the basis of need, regardless of age, severity of injury or other characteristics
- Service function - assessment (Outreach Teams); case management; support; education for individuals with ABI, their families and services providers; rehabilitation (direct therapy and therapeutic aid/assistance); life enrichment programming (meaningful activity); avocational programming (productive activity); vocational activity (return to work skills and experience); and crisis management
- Geographic reach/close to home

Advances in medical technology have resulted in our ability to preserve and prolong the lives of survivors of acquired brain injury. Still, the unique and long-term needs of individuals with moderate and severe acquired brain injury are often inadequately addressed when the transition from acute care centres to community-based service occurs. Often families and communities are ill prepared to deal with the diverse challenges demonstrated by survivors after the acute care phase of recovery.

The Partnership began as a vision based on the work of a group of people concerned about addressing gaps in services. In the early 1990s when the Partnership was conceptualised little research existed regarding a system of community-based service provision for survivors of brain injury and their families/caregivers. Research that did exist tended to focus on survivors in varying forms of acute and inpatient rehabilitation with little evaluation on the impact of services for survivors who receive service outside of those domains. As the intent of the Partnership was to provide service on a province-wide basis, a great deal of the information gleaned from the literature informed the development of a system that included service to both urban and rural centres over a vast geographical area, but did not provide a definitive model for Saskatchewan.
In the initial planning stages of the Partnership, several ABI project managers conducted site visits to other jurisdictions to review models of service delivery for survivors of ABI. Although these site visits helped to inform and provide direction for the Partnership, the model developed is quite distinctive. This service delivery model was unlike any other in

Saskatchewan or other parts of the country, so mechanisms for conducting program evaluation were required from the implementation phase to the outcome phase of the program.

Supported by relevant literature, this section provides an overview of the Saskatchewan model of service delivery for survivors of ABI and their families/caregivers. Support in the areas of case management, coordinated care, community reintegration, residential support, community-based slow stream rehabilitation, vocational programming, independent living, support services for families/caregivers and education and prevention initiatives are documented.

The Partnership model is based on the philosophy that survivors of ABI may require different services at each stage of recovery and that often times life-long services are necessary to enhance quality of life and provide enrichment. A recent study conducted by Lannoo, Brusselmanns, Van Eynde, Van Laere, and Stevens (2004), reviews the connection between the prevalence of and the need for long-term supports for survivors of acquired brain injury. With the assistance of physicians within the region of Flanders, Belgium, these researchers were able to develop a registry that included a representative sample of the ABI population as well as other data including age, time of injury, nature of injury, residual disabilities, and specific needs. Working with a sample size of 186 patients with ABI the study found that "in approximately two-thirds of the patients cognitive, emotional/behavioral, social, and/or vocational disabilities were reported" and that, "almost half of the patients were having mobility problems and approximately one-third were reported to have relationship problems" (p. 205).[3] Beginning with case management services offered through the Outreach Teams, survivors of ABI have the opportunity to access stream-lined services through the Partnership immediately upon leaving acute care. According to Whitman (1991), "case management in its broadest scope serves to coordinate and integrate services, resources, communication, and expectations among the patient, family, treatment team and payer" (p.19).[4]

In addition to acting as the primary case managers, members of the multidisciplinary Outreach Teams are equipped to provide service related to cognitive, emotional, behavioral, social and vocational disabilities, as well as those related to physical rehabilitation needs. Once the survivor returns home the Outreach Teams coordinate services as close to home as possible while utilizing additional Partnership components and/or services readily available within the community.
Delivery of services as close to home as possible is one of the main tenets of the Partnership and is reflected in the provision of a variety of community-based service components. Independent living programs, a/vocational services, community rehabilitation services, day programming and supported living services can all be accessed through the Partnership. The Lannoo, Brusselmanns, Van Eynde, Van Laere, and Stevens (2004) study cited earlier, indicates, "over half the patients were reported to have specific unfulfilled needs, of which 31 had living needs, 51 daytime activity needs

[3] Lannoo, E., Brusselmanns,W., Van Eynde, L., Van Laere, M., and Stevens, J. (2004). Epidemiology of acquired brain injury (ABI) in adults: prevalence of long-term disabilities and the resulting needs for ongoing care in the region of Flanders, Belgium. *Brain Injury*, 18(2), 203-211.
[4] Whitman, Mona. (1991).Case Management in Head Injury Rehabilitation. *Rehabilitation Nursing*, 16 (1), 2-5.

and 79 needs for specific ambulant care at home. The need for supported living was present in 22 cases of whom no less than 17 lacked this specialized care" (p.207).[5] The findings of this research indicate that the components of the Partnership are well suited to serve the varying needs of this population.

An important function of community-based programs is to meet the needs of survivors with a goal of increased community reintegration. Eighty-four percent individuals registered to Partnership programs live either independently or supported within their own or family homes. Survivors, by their residential setting, are situated to improve opportunities for community integration. In reference to community integration programs, Willer and Corrigan (1994) point out that rehabilitation within the inpatient setting does not allow the individual to resume their normal social roles leading to the goal of community integration. In fact, "the longer the individual is hospitalized the more difficult it can be to return to pre-injury role activities" (p. 648).[6] Providing home and community-based services through the Partnership has provided an inherent link to enhanced community integration for survivors of acquired brain injury.

Evidence in support of home and community-based services for survivors of acquired brain injury has also been documented by Batavia et al. (1991), who make a case for the Independent Living Model of long-term care for people with disabilities. "For disabled people generally, there are three likely negative consequences if their basic physical needs are not met. First, the individual will not be able to participate in gainful employment, will be limited in his or her ability to contribute to community and family life and will generally experience a poorer quality of life" (p.524).[7] The Partnership program has attempted to address the every day living needs of survivors through the funding of Independent Living Programs, supported living arrangements and life enrichment programs. While many survivors of acquired brain injury do require assistance with day-to-day activities, they are not in need of institutional care. The ability to reside in the community is the first step in achieving community integration. However, if meaningful relationships and productive activities are absent this can have a profound effect on an individual's perceived quality of life.

Depending on the type of injury, severity of injury, and years post injury, survivors can enter the continuum of services at various stages of rehabilitation. Currently there are many questions surrounding the rehabilitative outcomes of those individuals that are deemed not suitable for acute brain injury rehabilitation programs. Gray and Burnham (2002) argue that "low cognition and limited physical functioning may preclude some survivors as candidates for these programs and that they may be discharged to non specialized facilities", where their general health may decline even in areas unrelated to the injury (p.1447).[8]

---

[5] Lannoo, Brusselmanns, Van Eynde, Van Laere, and Stevens, 207.
[6] Willer, B., & Corrigan, J. (1994). Whatever it Takes: a model for community-based services. *Brain Injury*, 8 (7), 648.
[7] Batavia, I.E., De Jong, G., McKnew, L.B. (1991). Toward a National Personal Assistance Program: The Independent Model of Long-term Care for Persons with Disabilities. *Journal of Health Politics,Policy and Law*, 16 (3), 523-545.
[8] Gray, S.D., & Burnham, S.R.(2002). Preliminary Outcome Analysis of a Long-Term Program for Severe Acquired Brain Injury. *Archives of Physical and Medical Rehabilitation*, 18, 1447-1456.

The problem with acute brain injury rehabilitation according to Gray et al. is that rehabilitation is measured in weeks whereas there is considerable evidence suggesting that, "survivors of severe ABI are capable of significant gains months or even years post injury", even without the intervention of formal rehabilitation (p.1006).[9] The community-based rehabilitation components of the Partnership are based on the practices of slow stream rehabilitation taking into account that rehabilitative gains can occur over longer periods of time. During the developmental stages of the Partnership the need for slow stream rehabilitation services was reviewed and taken into account when deciding that the group targeted for services would include those individuals up to three years post injury.

Many survivors of ABI are not able to re-enter competitive work, but for those that are able vocational rehabilitation services play an integral role. A recent study conducted by Gamble and Moore (2003) explored the relationship between vocational rehabilitation services and employment outcomes of individuals with traumatic brain injuries. Data collected for this study was obtained from client reports included in a database managed by a public rehabilitation agency. In total 1,073 client files were reviewed consisting of only those clients who had received six distinct vocational rehabilitation services (p.32).[10] The results of this study indicate "favorable employment outcomes for individuals with TBI following participation in supported employment." The authors go on to report that, "the odds of obtaining competitive employment for clients receiving job placement services were 20.77 times the odds of obtaining competitive employment for consumers not receiving job placement services"(35).[11] Supported employment services have been provided by the Partnership since its inception and have proven essential in contributing to the quality of life for those survivors who are able to resume their pre-injury employment activities or enter a new form of employment.

Caring for a survivor of an acquired brain injury can have an enormous effect on family members and caregivers. Sources of stress can be related to behavioral difficulties, physical/cognitive impairments, financial burden and changing social roles. Mauss-Clum and Ryan as cited in Kolakowsky-Hayner et al. (2001) found that information surrounding the survivor's medical condition and a discussion of realistic rehabilitation expectations were reported the greatest needs (p.375).[12] In discussing long-term supports, research conducted by Ponsford, Olver, Ponsford and Nelms (2003) found that relatives of survivors show an increased subjective burden from three to five years post injury and that this burden still, has not been reduced by 7 years (p.465).[13] Family members and caregivers can access numerous supports through the Partnership, including education, information, counseling and advocacy services. Caregivers, like survivors, are in need of long- term supports, and the Partnership has also funded support groups to meet this desired need.

9

10

[11] Gamble, D., & Moore C., (2003). The Relationship between VR Services and Employment Outcomes of Individuals with Traumatic Brain Injury. *Journal of Rehabilitation*, 69 (3), 32, 35.

[12] Kolakowsky-Hayner, S.A., Miner, K., & Kreutzer, J. (2001). Long-Term Quality and Family Needs After Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation*, 16 (4), 375.

[13] Ponsford, J., Olver, J., Ponsford, M., &Nelms, R. (2003). Long-term adjustment of families following traumatic brain injury where comprehensive rehabilitation has been provided. *Official Research Journal of the International Brain Injury Association*, 17 (6), 465.

The Provincial Education and Prevention Coordinator directs the education and prevention component of the Partnership. Based on current research and trends in injury, services and strategies are developed at the provincial level and then used to inform the daily activities of the regionally situated Education and Prevention Coordinators. *The Economic Burden of Unintentional Injury in Saskatchewan* states that, "In 1998 preventable injuries cost the people of Saskatchewan $595 million dollars or $576 dollars for every citizen" (p.3).[14] According to Thurman et al. as cited in Cusimano, FACS and K.Mukhida (2003), TBI is responsible for more trauma death than injury to any other region of the body, accounting in most countries for 50% or more of all traumatic deaths" (p.5).[15] Given this reality, a provincially coordinated effort in the area of injury prevention is well warranted. In support of this concept, Christoffel and Gallagher (1999) maintain that health departments are appropriate lead agencies for injury prevention strategy development and coordination because they combine regulatory authority, program funding and provision of services at the local level as well as public education.[16]

Injuries cost the Province of Saskatchewan a great deal both financially and in terms of human suffering and loss. All efforts to reduce the risk of injury are important but should be strategic and make efficient use of resources. The funding from the Partnership has allowed networking among agencies and individuals that has led to less of a duplication of resources.

Saskatchewan Institute on Prevention of Handicaps

[14] Smartrisk. *The Economic Burden of Unintentional Injury.* (2001) 3.

[15] Cusimano M.D., & Mukhida, (2003). Acute Injuries Research in Canada. Background paper for the Canadian Institute for Health Research Listening for Direction in Injury Regional Workshops. 5

[16] Christoffel ,T. & Gallagher S. (1999) *Injury Prevention and Public Health: Practical Knowledge, Skills and Strategies.* Gaithersburg, MD: Aspen Publishers Inc.

Acquired Brain Injury Partnership Program
Service Continuum

The Acquired Brain Injury Partnership Project, in line with best practice evidence,[17] provides a continuum of community-based services for persons who have acquired a brain injury and their families. Prevention activities are a component across the service continuum (see flow chart on page 21). The Partnership services link the client from acute care and inpatient rehabilitation by providing transitional community-based rehabilitation and reintegration services.

The Partnership has the unique ability to bring together multiple service providers to address client need in an integrated manner. The range of services are summarized as follows: assessment (Outreach Teams); case management; support; education for individuals, families and services providers; rehabilitation (direct therapy and therapeutic aid/assistance); life enrichment programming (meaningful activity); avocational programming (productive activity); vocation activity (return to work skills and vocational experience); and crisis management services. Each forms an integral component of the continuum.

For many people who sustain an acquired brain injury their first point of contact with the Partnership is through a referral from an acute-care setting. Once it is determined that a client meets the criteria for service a member of the Outreach Team takes part in discharge planning from acute care and assumes the role of primary case manager until an assessment is completed and other referral sources are determined. Quite often referrals are dictated by where a client lives and the types of services that are available in or near their communities. Although Outreach Team members act as primary case managers they also provide direct therapy when a needed service in a specific professional field is unavailable in a client's home community.

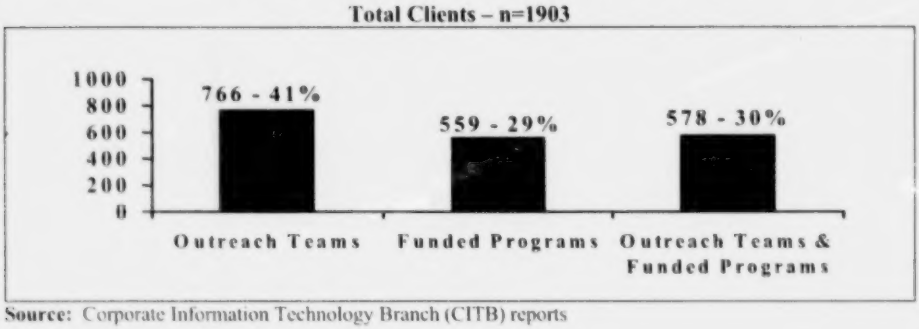
A common referral for the Outreach Teams is to one of the seven Regional Coordinators located throughout the Central and Southern regions of the province. At this time the Coordinators would assume the role of primary case manager and coordinate service for the client as close to their home as possible. However, depending on the individualized needs of a client, the Outreach Team may refer beyond the Coordinators and make a direct referral to another Partnership Program.

Factors including, date of injury, extent of injury, and rehabilitation needs, may also mean that clients bypass the Outreach Team(s) and Regional Coordinator(s) altogether and access service at another point along the continuum. Frequently clients only have contact with either an Outreach Team or Funded project. (See Figure 1)

---

[17] Burke, D.C., (1995). Models of Brain Injury Rehabilitation. *Brain Injury*, 9 (7), 735-743.

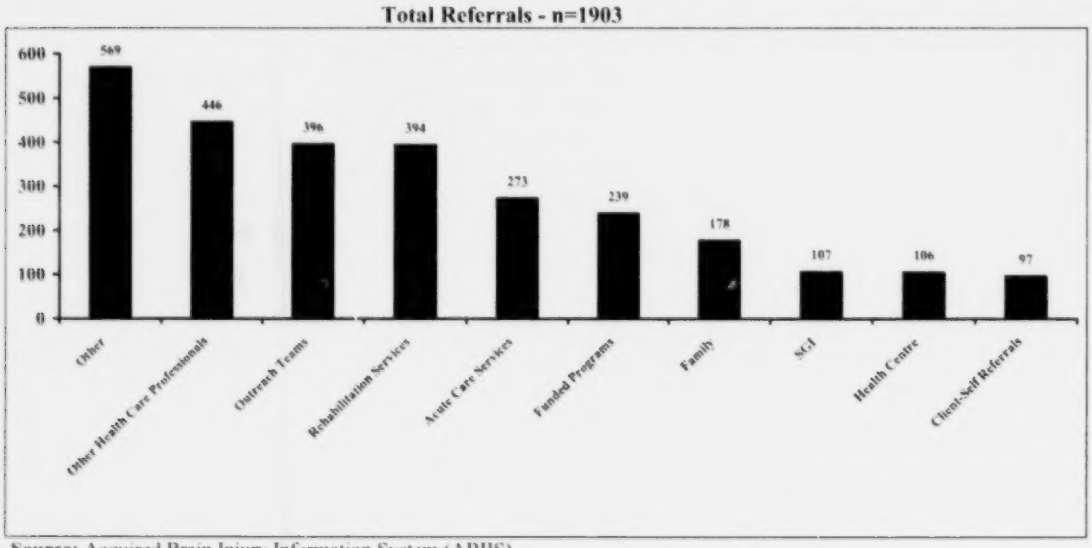
Figure 1: Clients Seen By Funded Programs and Outreach Teams
For the Period Jan 1, 2000 – March 31, 2003



Source: Corporate Information Technology Branch (CITB) reports

Although a strong link exists between the Outreach Teams and funded projects, referral patterns indicate that a greater number of clients access Partnership services via other health care professionals, rehabilitation services, and other organizations/departments (See Figure 2).

Figure 2: From Referral Source by each Category
For the Period Jan1, 2000 – March 31, 2003



Source: Acquired Brain Injury Information System (ABIIS)

The referral patterns suggest that there is increased coordination and integration of ABI services within the province. The Partnership has been successful in linking services for individuals with ABI at both the regional and community levels. The great numbers of referrals seen outside of Partnership programs show that the services provided by Partnership are well known and that service providers refer to areas outside of the Partnership when necessary.

Service Components

The ABI Pilot Project began in 1996 with 16 programs. Now known as the Acquired Brain Injury Partnership Project, it has expanded to thirty-six community based programs and 7 prevention and education programs including:

- 3 multidisciplinary Outreach Teams
- 7 Community Coordinators
- 2 large-scale Residential Programs
- 7 Rehabilitation-based programs
- 1 Children's program
- 7 Prevention and Education programs
- 6 Avocational/Vocational programs
- 2 Day Programs
- 5 Independent Living Programs
- 2 Crisis Management Programs
- 1 Family/Client Support Program

Outreach Teams

Note: brackets denote number of programs by region

Regions - North (1), Central (1), South (1)

The three regionally placed Outreach Teams based in Prince Albert, Saskatoon and Regina coordinate service on a province-wide basis. While at times providing direct client care, the main function of the Outreach Teams is to apply a multidisciplinary approach to client case management. The Outreach Teams assess client need and ability, and then assist clients and their families in navigating through the system of services and supports for individuals with ABI, with the overall goal of successful community reintegration and improved quality of life.

Regional Coordinators

Regions - Central (2), South (5)

There are seven ABI Regional Coordinator positions within the province located in Estevan, Weyburn, Swift Current, Yorkton, Moose Jaw, Wilkie and Humbolt. The goal of the Regional Coordinators is to work in partnership with each client/family member, the community and other health care professionals to promote and achieve successful community integration. Like the Outreach Teams the Regional Coordinators work to bridge the gap in service between acute care/rehabilitation and the community. They assist the survivor through the community reintegration process while focusing on an optimal quality of life for the survivor and family.

Independent Living Worker Programs

Region - South (4)

There are four Independent Living Workers (ILWs) operating out of SMILE Services (Estevan), Weyburn Group Homes Society (Weyburn), SIGN (Yorkton) and VON (Moose Jaw). The ILWs participate in the coordination of services for ABI clients with the assistance of the Regional Coordinators, other health care professionals and community agencies. When services cannot be arranged close to home, the ILWs provide individualized direct care and support. Services include, but are not limited to, life skills, rehabilitation, recreational activities and a/vocational support.

Residential Options

Regions - North (1), Provincial (1)

There are two Residential Options programs dedicated to serving the needs of survivors. Phoenix Residential Society is situated in Regina and is mandated to act as a provincial resource, and Prince Albert Residential Options that serves the North Region. The goal of the Residential Options programs is to enable individuals with ABI to live more independently in the community by assisting in the restoration of as much functional ability and quality of life as is possible.

Rehabilitation Assistants

Region - North (2), Central (1)

There are three Rehabilitation Assistants in the north and central regions located in Beaval, La Ronge, and Meadow Lake. The goal of the rehabilitation assistants is to restore, maintain and enhance function and quality of life. Due to the limited availability of services in the north and the vast geographical coverage area these positions were created to provide services to the most remote areas of the province.

Speech and Language Pathologist

Region - North (1)

Located in Melfort, the continuum employs one Speech and Language Pathologist. The goal of the Speech and Language Pathologist is to enhance the communication skills and improve the quality of life for individuals with acquired brain injuries and their families, as well as increase the public's knowledge and understanding of brain injuries.

Children's Program

Region - Central (1)

Radius Community Centre, located in Saskatoon is the only program within the Partnership that offers programming exclusively for children and adolescents. The goal of the Community Integration Program is to facilitate age appropriate integration opportunities for children and youth with acquired brain injury in their own community.

Rehabilitation Programs

Regions - North (1), Central (1), South (1)

There are three regionally placed branches of the Saskatchewan Association for the Rehabilitation of the Brain Injured (SARBI) located in Regina, Saskatoon and Kelvington. The goal of SARBI is to provide a volunteer-delivered program focussed on increasing the independence of persons who have incurred a brain injury. Based on the model of slow-stream rehabilitation programs, it involves physical activity and exercise, recreation and leisure activities as well as occupational therapy and social skill development.

Vocational Programs

Regions – Central (1), South (2)

The Saskatchewan Abilities Council (SAC) in Regina and Saskatoon and Career Headways Inc. in Regina provide individualized support and training/rehabilitation to survivors who are interested in obtaining and maintaining employment. The goal of the vocational programs is to improve the quality of life of survivors by enhancing community integration and increasing functional productivity. For clients attending Career Headways, this may also mean returning to school.

Life Enrichment Programs

Regions - North, Central, South

There are also three ABI Life Enrichment Programs operating out of the Regina, Saskatoon and Yorkton branches of the Saskatchewan Abilities Council (SAC). These programs are designed to promote and facilitate personal and social rehabilitation for ABI survivors that may or may not be capable of returning to the competitive workforce.

Crisis Management Programs

Regions - Central (1), South (1)

Crisis Intervention Services located in Saskatoon and Mobile Crisis Services located in Regina, both provide crisis management services for survivors of ABI. The overall goal of these programs is to facilitate community reintegration by linking survivors of ABI with the most appropriate services. When mainstream services have been unsuccessful in meeting client needs these agencies provide crisis intervention, service coordination and case management services for survivors and their families.

Day Programming

Region - Central (2)

Lloydminster Acquired Brain Injury Society (LABIS) offers day programming two days per week for survivors of ABI. Programming includes physical and cognitive exercise and life skills with an overall goal to promote independence and community integration.

Sherbrooke Community Centre (Saskatoon) offers day programming two days per week for survivors of ABI. The program is intended to increase client skills in the areas of communication, interpersonal relations and life skills. The goal of the program is to assist survivors of acquired brain injury to develop psychosocial and independent living skills to provide life enrichment by enabling them to access community resources.

Provincial Organizations

A provincial grassroots organization, the Saskatchewan Brain Injury Association (SBIA), located in Saskatoon, provides support to survivors and families in the form of groups, supportive services and resource development.

The Saskatchewan Institute on Prevention of Handicaps (SIPH) located in Saskatoon, develops user-friendly, accessible resources to professionals and the public to prevent acquired brain injury in children.

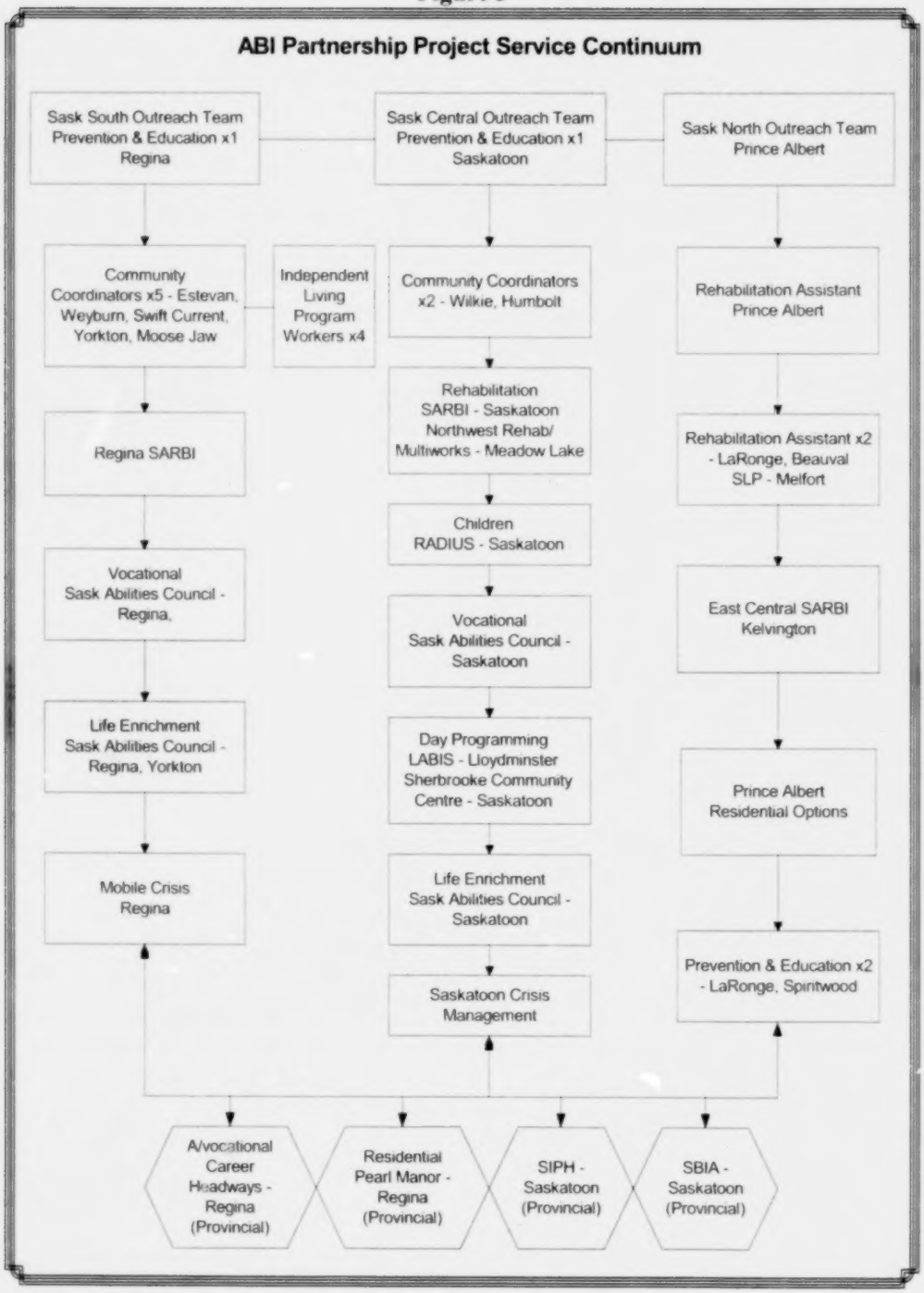
Education and Prevention Coordinators

Region - North (2), Central (1), South (1)

There are four positions within the Partnership specifically dedicated to education and prevention initiatives. Both the South and the Central Outreach Teams include Education and Prevention positions. As well, there are two northern positions, located in La Ronge and Spiritwood. The goal of the Education and Prevention Coordinators is to assist communities in developing effective injury prevention strategies and to raise the awareness of the effects of ABI through ongoing education initiatives.

Although a complete continuum of service is available for survivors of ABI and their families, the range of services offered is more concentrated in the southern region of the province. Population demographics for the province support this distribution of ABI services. Further, analysis conducted on a regional basis has shown that the number of ABI clients in the south is notably higher than in the central or northern regions. Further investigation is necessary in order to determine why program uptake (i.e., greater number of discrete, registered clients) is greater in the south.

Figure 3

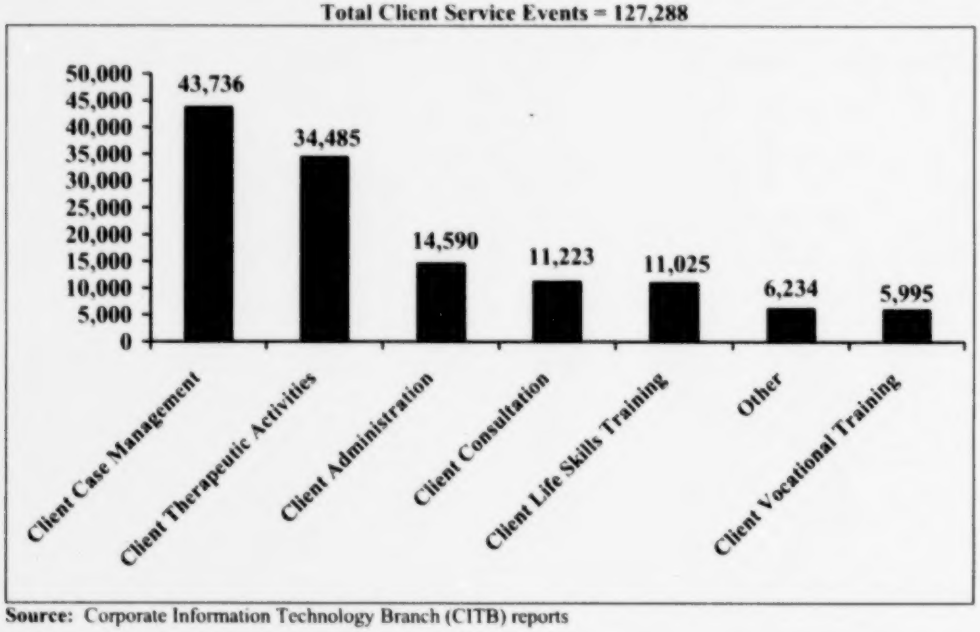

ABI Partnership Project Service Continuum
Sask South Outreach Team Prevention & Education x1 Regina
Sask Central Outreach Team Prevention & Education x1 Saskatoon
Sask North Outreach Team Prince Albert
Community Coordinators x5 - Estevan, Weyburn, Swift Current, Yorkton, Moose Jaw
Independent Living Program Workers x4
Community Coordinators x2 - Wilkie, Humbolt
Rehabilitation Assistant Prince Albert
Regina SARBI
Rehabilitation SARBI - Saskatoon Northwest Rehab/ Multiworks - Meadow Lake
Rehabilitation Assistant x2 - LaRonge, Beauval SLP - Melfort
Children RADIUS - Saskatoon
Vocational Sask Abilities Council - Regina,
Vocational Sask Abilities Council - Saskatoon
East Central SARBI Kelvington
Life Enrichment Sask Abilities Council - Regina, Yorkton
Day Programming LABIS - Lloydminster Sherbrooke Community Centre - Saskatoon
Prince Albert Residential Options
Mobile Crisis Regina
Life Enrichment Sask Abilities Council - Saskatoon
Prevention & Education x2 - LaRonge, Spiritwood
Saskatoon Crisis Management
A/vocational Career Headways - Regina (Provincial)
Residential Pearl Manor - Regina (Provincial)
SIPH - Saskatoon (Provincial)
SBIA - Saskatoon (Provincial)

Scope of Service

The client service event chart below (Figure 3) demonstrates that service capacity has substantially increased for individuals with ABI. Partnership service providers are providing a range of case management and support services. The top five service event categories comprising 90% of service offered, fall within the following service event categories: client case management, client therapeutic activities, client administration, client consultation and client life skills training.

Of a total of 127,288 service events provided by the Partnership between Jan 1, 2000 and March 31, 2003, the three multidisciplinary outreach teams (ORTs) located in Regina, Saskatoon and Prince Albert provided 48,953 service events or 38.5% of that total.

Figure 4: All Programs - Client Service Events
For the Period Jan 1, 2000 – March 31, 2003



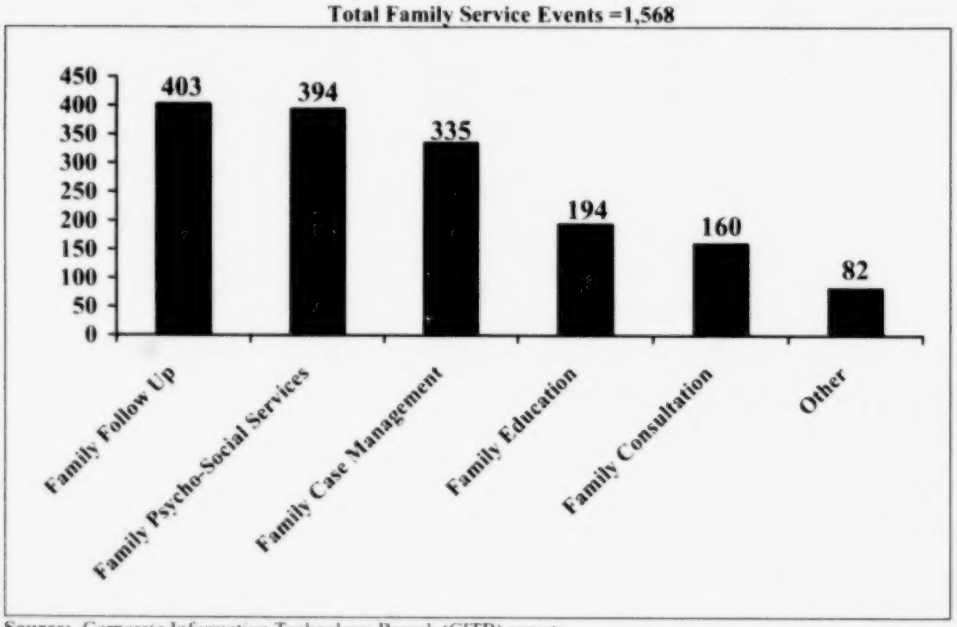
Source: Corporate Information Technology Branch (CITB) reports

Services Provided to Families/Caregivers

As the quality of life for clients in the ABI Partnership can depend largely on the extent to which they receive support from their families/caregivers, a main principle of the ABI Partnership has been to provide ongoing supportive services to families/caregivers. Although all Partnership projects offer either formal or informal support for family members/caregivers, the outcome of these activities is unclear at this time. Due to the sheer magnitude of the current evaluation, focusing on program and client outcomes, evaluation of family member/caregiver satisfaction was not conducted. However, qualitative information regarding family/caregiver satisfaction with the program was gathered during the implementation phase of the project and demonstrated a high degree of satisfaction. An evaluation of support services for family members/caregivers is currently in the planning stages and will be initiated during the next phase of funding.

The table below outlines the number and types of family/caregiver service events recorded in the ABIIS. It is speculated that the number of family service events is inaccurate due to the fact that numerous family/caregiver consultations occur on an informal basis and therefore are not reported. Follow up with programs should occur in order to more accurately reflect the type and scope of family services offered.

Figure 5: All Programs – Family Service Events
For the Period Jan 1, 2000 – March 31, 2003



Source: Corporate Information Technology Branch (CITB) reports

Allocation of Funding Dollars

The Outreach Teams receive the bulk of program funding at 38.1%, followed by the two large-scale residential programs at 13%. Prevention and Education activities are also well resourced at 11.4% of the annual budget. These three components account for 63% of total budget. Table 3 below itemizes percentage of funding in 2002 by major program components. (See also the map in Appendix B that provides detailed budget breakdowns by geographic region for the 1999-2003-contract period).

Table 3: Funding by program component – Calendar Year 2002

Program Component	**2002 Funding***	**% of Total Funding**
Total - All Programs	**$3,782,649**	100
Outreach Teams (3) – includes north Rehab Assistant for SNORT + Family Flex funds	$1,442,988	**38.1**
Prevention and Education funded programs (7) – includes Provincial Coordinator	$333,652	
Education and Prevention special projects	$96,103	
Total Prevention and Education	**$429,755**	**11.4**
Program Coordinators (7)	$357,556	9.5
Career Headways - Intensive Life Skills (1)	$60,948	1.6
Rehab – North (3) + Central (1)	$180,737	4.8
Crisis Management (2)	$73,317	1.9
Children (1)	$91,087	2.4
Independent Living Program (4)	$101,384	2.7
Day Programming (2)	$21,473	.6
SBIA – Support (not including education component)	$50,315	1.3
SARBI (3)	$130,084	3.4
Avocational (3)	$71,641	1.9
Vocational (2)	$128,959	3.4
Residential (2)	**$492,096**	**13.0**
Provincial support (Health - 2.4)	$146,113	3.9
Other (Vocational Assessment)	$4,196	

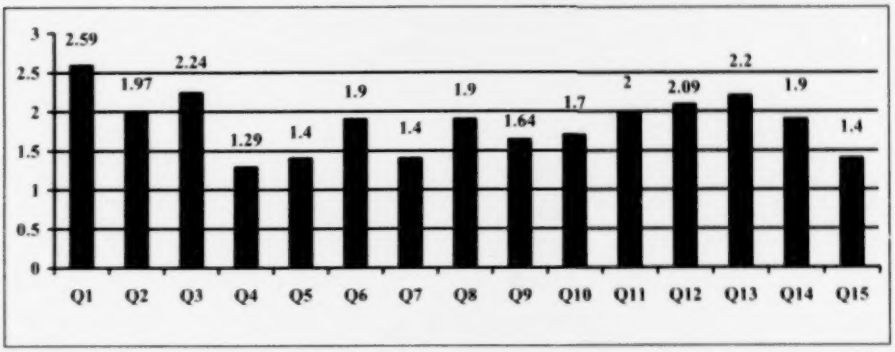
Source: *SGI Budget Actuals

Acquired Brain Injury Partnership Project Service Provider Survey

In May 2003 the Provincial ABI Office distributed a service provider survey to all funded agencies (43 agencies or approximately 66 full-time equivalent (FTE) staff) to determine service provider opinion on project management and provincial support for the ABI Partnership Project. The survey was based on a five-point likert scale and also included a section of four open-ended questions. Thirty-four of sixty-eight surveys were completed and returned resulting in a response rate of approximately 49%. The total overall rating was a mean of 1.8, with 1 representing "strongly agree".

Service providers indicated an overall level of satisfaction with the support provided by the Provincial Office but would like more support in the areas of financial management and program evaluation (see Appendix C for questionnaire and Appendix D for qualitative responses).

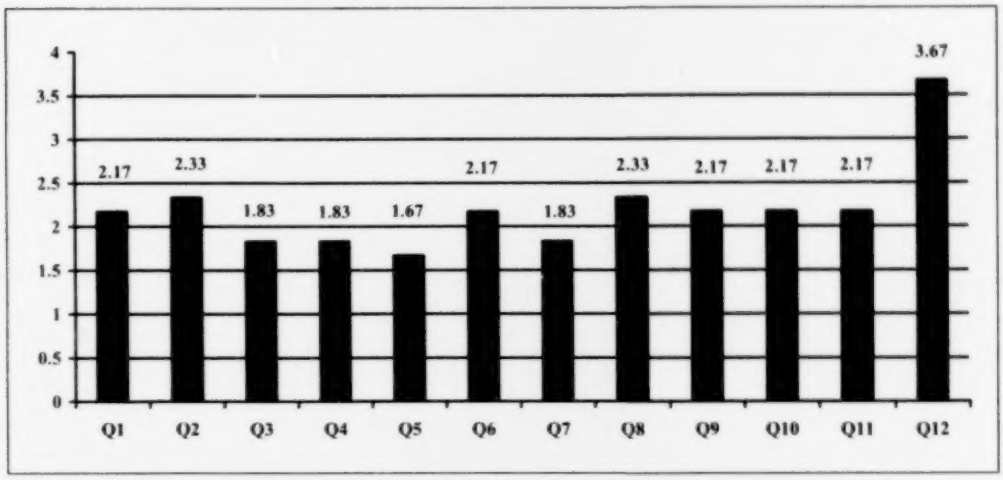
Figure 6: Service Provider Survey - *Quantitative Results*



Saskatchewan Government Insurance Personal Injury Representative (PIR) Survey

In May 2003 the Provincial ABI Office distributed a survey to 11 SGI staff. The survey, based on a five-point likert scale, also included a section for qualitative (open-ended) responses. Six of eleven possible surveys were returned for a response rate of 55%. The total overall rating was calculated at 2.19, with 1 representing "strongly agree". Information obtained from the survey responses indicates that the PIRs are generally satisfied with the services provided by the Partnership but suggests that communication between Partnership programs and SGI could be improved (see Appendix E for questionnaire and Appendix F for qualitative responses).

Figure 7: PIR Survey - *Quantitative Results*



CLIENT OUTCOMES

Evaluation Question 5: Has quality of life and community integration increased for individuals with ABI and their families?

I. Saskatchewan Outcomes Questionnaire (SOQ)

A provincial committee with experience in evaluation developed the SOQ. The SOQ committee utilized pre-existing questionnaires (e.g., the Community Integration Measure and the Quality of Life survey) and also developed new questions to measure other areas such as productivity and functional interdependence.

The questionnaire focuses on measuring improvements in function in the areas of: **1) community integration, 2) productivity, 3) quality of life, 4) social integration and 5) functional interdependence** for people with brain injury.

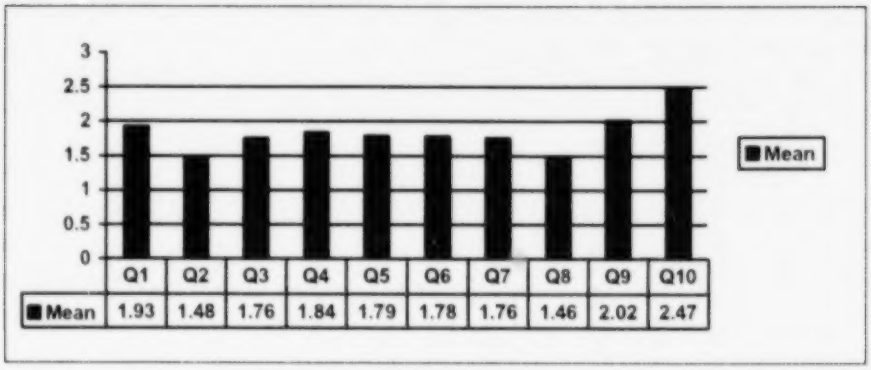
The SOQ is a 50-item, mail-out, self-report survey instrument that has been administered since February 1999 to ABI clients registered in the Partnership. While the instrument is still administered to active clients on specified anniversary dates, it was replaced by the Outcomes Questionnaire package in February 2002 and is therefore no longer administered to new clients.

Data included in analysis includes results from: baseline (n=486), 6-month (n=145) and 1-year (n=52) time intervals.

The data was analysed based on three subscales: 1) community integration (Questions 1-10), 2) safety (Questions 11-17), and 3) quality of life (Questions 20-32). Baseline results of the SOQ showed that clients' self-report at the Wave 1 time interval indicates that they were doing well across all three subscales of the survey – clients reported strong agreement to questions measuring community integration, quality of life and safety.

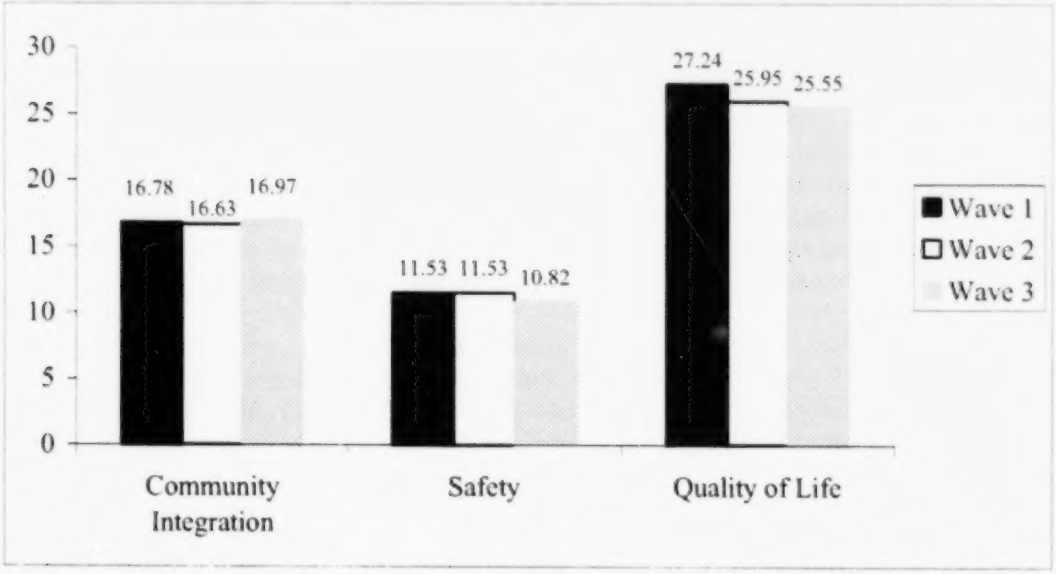
Questions 1-10 of the SOQ comprise the Community Integration portion of the survey (see Appendix G). On a 5-point likert scale, with 1 being "Always Agree" and 5 being "Always Disagree", total agreement = 10 and total disagreement = 50. The CIM score was 18.3, which shows strong agreement and therefore good levels of community integration at the baseline time interval. Detailed responses to each question are itemized in Figure 8 below.

Figure 8: SOQ – Community Integration – Wave 1 Responses



While the Wave 1-3 comparison did not yield statistically significant results, it does reveal an interesting trend. The overall rating on the three subscales shows no significant change between the three waves which could indicate that this sub-sample of respondents (n=52) is at minimum maintaining its functional status at one-year in the community (see Figure 9 presented below).

Figure 9: Saskatchewan Outcomes Questionnaire – Wave 1-3 Comparisons



II. Case Studies - 23 programs conducted client case studies. Many programs presented more than one case study and therefore a total of 43 case studies were presented. Thirty-four of these case studies presented successful client outcomes in terms of quality of life and community integration goal attainment.

Of 20 clients whose case study revealed successful outcomes their goal attainment was identified and reported under the following themes/areas:

Table 4: Case Study, Client Successful Goal Attainment, N=20

Top 8 Goals	% Goal Obtained
Vocational/Productive Activity	65%
Life Enrichment Activity	70%
Activities of Daily Living (ADL)	45%
Physical	65%
Independence	50%
Cognitive	40%
Community Integration	55%
Psycho-Social	75%

A summary of the nine unsuccessful cases presented demonstrates that client motivation, insight and acceptance are all key attributes in their successful goal attainment toward recovery and rehabilitation from the deficits caused by brain injury.

Overall, the case study findings show that individuals registered in programs funded under the ABI Partnership Project demonstrate significant progress toward goal attainment and concurrently demonstrates how funded programs' activities serve to support clients in meeting their needs and improving their quality of life.

III. Client Outcomes Questionnaire Package

The Outcomes Questionnaire Package has been administered since February 2002. It was compiled with the intent to replace the SOQ. It is comprised of the following questionnaires: Mayo Portland Adaptability Inventory - (self), (staff), and (other); Community Integration Measure; Orientation to Life; Quality of Life; and the Problem Checklist.

Mayo Portland Adaptability Inventory (Mayo-Portland) – is a 30-item mail-out questionnaire measured on a 3-point likert scale with 0 being "No impairment" and 3 being "Severe impairment/problem/lack of (friends/family)". Three separate questionnaires are administered – Self, Staff and Other (e.g., caregiver). The Mayo Portland measures physical, mental and emotional rehabilitation.

Community Integration Measure (CIM)– is a 10-item mail-out questionnaire measured on a 5-point likert scale with 1 being "Always Agree", 3 being "Neutral" and 5 being "Always Disagree". The CIM measures community integration.

Orientation to Life – is a 29-item mail-out questionnaire measured on a 7-point likert scale with 1 being "Never" and 7 being "Always". The Orientation to Life measures quality of life and acceptance.

Quality of Life – 13-item mail-out questionnaire measured on a 5-point likert scale with 1 being "Always Agree", 3 being "Neutral" and 5 being "Always Disagree". The Quality of Life measures quality of life.

Problem Checklist – 43-item mail-out questionnaire. It measures closed-ended Yes/No responses to a series of problems, and then measures the severity of the problem by a 7-point likert scale with 1 being "No Problem" and 7 being "Severe Problem". The Problem Checklist measures productivity and independence.

Saskatchewan Health contracted with University of Regina Department of Psychology Professor Donald Sharpe to conduct the statistical analysis of this questionnaire package. A package of **127** Wave 1 (baseline/intake) and **22** Wave 2 (one-year anniversary/inactivation) de-identified questionnaires was provided for analysis.

Table 5: Client Outcomes Questionnaire Package

Wave One/Baseline Results				
Questionnaire	**N**	**Mean**	**Range**	**Standardized Score**
Mayo Portland Adaptability Inventory (Mayo) Self Physical/ Medical	94	3.9362	0-18	.22
Mayo Self Cognitive	96	5.8542	0-18	.33
Mayo Self Emotional	100	2.3600	0-9	.26
Mayo Self Everyday Activities	98	4.7449	0-15	.32
Mayo Self Social	99	1.5253	0-9	.17
Mayo Self Behaviour	92	1.7826	0-21	.08
Mayo Staff Physical/Medical	92	3.1739	0-18	.18
Mayo Staff Cognitive	95	4.4526	0-18	.25
Mayo Staff Emotional	95	1.2105	0-9	.13
Mayo Staff Everyday Activities	83	7.0120	0-15	.47
Mayo Staff Social	95	1.7368	0-9	.19
Mayo Staff Behaviour	92	1.6739	0-21	.08
Community Integration Measure	98	19.2041	10-50	.38
Quality of Life	96	27.7813	13-65	.43
Orientation to Life	85	135.5412	29-203	.33 (inverse)

Note: a lower score is better (i.e., represents higher agreement) for the Mayo, Community Integration Measure and Quality of Life questionnaires. Conversely, a higher score is better (i.e., represents higher agreement) for the Orientation to Life questionnaire.

In looking at the standardized scores in Table 5 above, the lowest scores (least degree of impairment) are seen on the **behaviour** domain of both the Mayo self and staff report. The highest scores (greatest degree of impairment) are seen on the Mayo staff report of function regarding **everyday activities**.

The Wave 1 results were also analysed looking at 10 demographic variables: Age, Ethnicity, Cause of Injury, Date of Injury, Living Situation, Insurance, Employment, Education, Region and Gender.

Of the four questionnaires analysed in this package, it was determined that the Mayo Portland Adaptability Inventory yielded the most useful, statistically significant data.

Wave 1 demographic findings of particular interest for follow-up include:

Age - At baseline, Mayo Portland self-report showed that young people (19-24 years) are doing medically/physically better than older people (50+ years).

Ethnicity - Lower scores were noted for Aboriginal respondents in **self**-report on the **cognitive, social behaviour** and **behaviour** domains of the Mayo Portland along with the Community Integration Measure and Orientation to Life measures. Corroboration is noted between the **self** and **staff** report of the Mayo Portland across the domains of **social behaviour and behaviour.**

Date of Injury - Lower levels of impairment are noted on the **physical/medical** and **everyday activity** domains of the Mayo Portland **self** report for those respondents whose injuries occurred prior to 1997 (i.e., greater than five years at time of questionnaire administration) compared to those respondents whose injury occurred within the last three years (i.e., 1999-2002). It may be found in the future that the recently injured group may have superior outcomes given more time.

Insurance - For insurance type, the Mayo Portland **staff** report indicated better functioning in the **emotion** domain for those with SGI-No Fault insurance over no insurance.

Conversely, better **Community Integration Measure** scores were seen for no insurance clients compared to SGI No Fault clients.

Employment - Community Integration Measure (CIM) scores were better for those employed full- or part-time compared to those unemployed.

While there were no statistically significant differences found between Wave One and Two, nonetheless six (6) out of nine (9) scales indicate improvement (i.e., lower scores are better with the exception of the Orientation to Life where a higher score is better) between Wave One and Wave Two. The mean scores are provided in Table 6 below for illustrative purposes.

Table 6: Wave One and Two Comparisons

Questionnaire	N	Baseline Mean (Average) Score	One-Year /Inactivation Mean (Average) Score
Mayo Self physical	21	2.90	2.71
Mayo Self Cognitive	20	5.75	5.35
Mayo Self Emotional	22	1.86	1.68
Mayo Self Everyday Activities	20	4.00	3.40
Mayo Self Social	21	1.04	1.04
Mayo Self Behaviour	19	1.58	1.84
CIM	20	17.8	18.6
Quality of Life	20	29.6	28.5
Orientation to Life	20	144.2	135.8

IV. Wascana Client-Centered Care Survey (Revised) - (WCCS-R)

The Wascana Client-Centered Care Survey (Revised) was utilized to ascertain client satisfaction with the services provided by agencies funded under the ABI Partnership Project. It is a valid and reliable instrument. Of the 1,650 discrete, registered clients receiving services between January 1, 2000 and June 30, 2002, a random sample of 799 clients was surveyed by mail-out. There was a 31% response rate (n=242). Ratings were determined on a 5-point likert scale, with 1 representing highly client-centered care. On the three subscales that comprise the WCCS-R, the ABI Partnership Project was rated at 1.84 on Consideration of Physical and Emotional Needs, 2.06 on Understanding and Participation in Care, and 2.27 on Facilitation of Community Care. The overall score was 2.01. The highest rated item of client-centered care was that clients consistently felt they were "treated with dignity and respect." The most common areas of concern were with the lack of integration of ABI services with other community services, and about being discharged from ABI programs before the client was ready. The survey also captured qualitative responses. Most qualitative responses were positive, in support of the work of the program.

Overall, the WCCS-R demonstrated a high level of client satisfaction with the services provided by the ABI Partnership Project.

EDUCATION AND PREVENTION

The Education and Prevention component of the Partnership has set out to address gaps in service as identified in the *Acquired Brain Injury: A Strategy for Services*:

> *...it is clear that the funding from the ABI Partnership Project has been a great benefit to parents and children throughout the province.*
>
> Saskatchewan Institute on Prevention of Handicaps

"There is no provincially coordinated effort for prevention of acquired brain injuries (ABIs), and since most ABIs occur in individuals under 35 years of age, and the 16 to 25 year age range is most at risk, there is a definite need for age appropriate prevention activities targeted toward children, youth and adults. Such prevention activities should also address issues of substance abuse including drinking and driving and its contribution to ABI."

Two main Education and Prevention goals have been identified to guide program activity:

Goal One – The number of ABIs in the province of Saskatchewan will be reduced.

Goal Two – Improved abilities of service providers, community, clients and their families to better cope with the impacts of their injuries.

Hospitalization Rates

An analysis of hospital separations data has revealed that the rate of hospitalizations for ABI has decreased over the 1987-1988 and 2000-2001 fiscal years (Source: CITB). The steepest decline is seen in the traumatic brain injury category. The decline seen in ABI hospitalization rates could be due to a number of factors. See Appendix H for further analysis of this data.

EDUCATION AND PREVENTION

The Education and Prevention component of the Partnership has set out to address gaps in service as identified in the *Acquired Brain Injury: A Strategy for Services*:

> *...it is clear that the funding from the ABI Partnership Project has been a great benefit to parents and children throughout the province.*
>
> Saskatchewan Institute on Prevention of Handicaps

"There is no provincially coordinated effort for prevention of acquired brain injuries (ABIs), and since most ABIs occur in individuals under 35 years of age, and the 16 to 25 year age range is most at risk, there is a definite need for age appropriate prevention activities targeted toward children, youth and adults. Such prevention activities should also address issues of substance abuse including drinking and driving and its contribution to ABI."

Two main Education and Prevention goals have been identified to guide program activity:

Goal One – The number of ABIs in the province of Saskatchewan will be reduced.

Goal Two – Improved abilities of service providers, community, clients and their families to better cope with the impacts of their injuries.

Hospitalization Rates

An analysis of hospital separations data has revealed that the rate of hospitalizations for ABI has decreased over the 1987-1988 and 2000-2001 fiscal years (Source: CIHI). The steepest decline is seen in the traumatic brain injury category. The decline seen in ABI hospitalization rates could be due to a number of factors. See Appendix H for further analysis of this data.

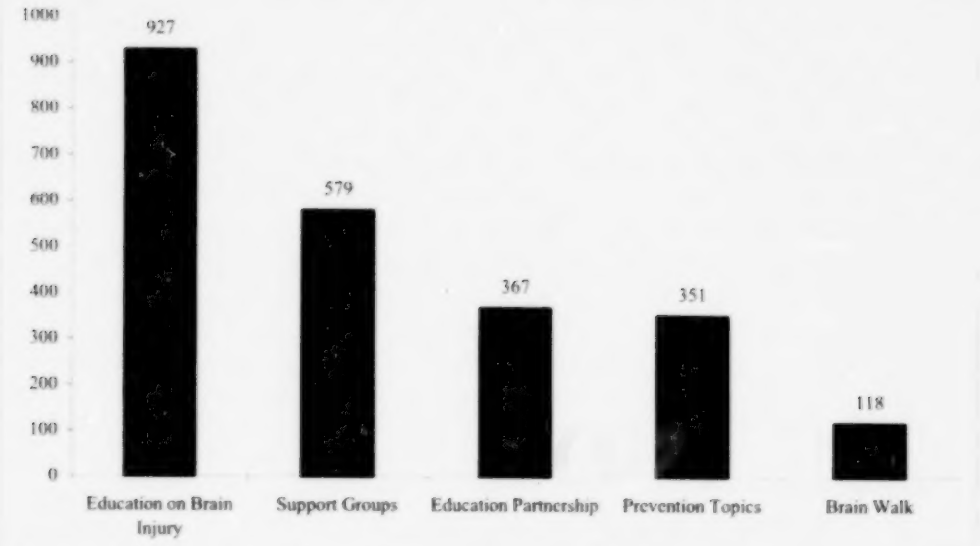
Evaluation Question 1: Has awareness of the community increased toward the prevention of ABI?

Community Service Events

Community service events conducted by Partnership Programs are dedicated to profiling injury prevention strategies and to raising the awareness of the effects of ABI. The figure below outlines, in total, the number and type of Community Service Events reported by the Prevention and Education Coordinators, the Outreach Teams, the Regional Coordinators and the Saskatchewan Brain Injury Association.

Figure 10: Community Service Events
For the Period Jan 1, 2000 – March 31, 2003

Total Community Service Events = 2,342



Source: Acquired Brain Injury Information System (ABIIS)

Provincial Education and Prevention Activities

Increased awareness and education regarding injury, and more specifically ABI, is demonstrated through the range of community based activities the ABI Partnership has facilitated, funded and/or partnered in:

- Since 1997 the Partnership has been involved with Brain Awareness Week as a partner and funding agency.

- There has been ongoing collaboration with the SGI Traffic Safety Department on the development of the Community Injury Prevention Grant program. To date there have been 848 projects funded for a total of $699,539.

- Funding has been provided to the Saskatchewan Institute on Prevention of Handicaps to coordinate resource development and community support in the area of child/youth injury.

- 147 projects have been funded in the area of impaired driving through the community grant program.

- The video *Dangerous Games* was created in partnership with Think First targeted to adolescents and young teens.

- Preliminary meetings have been held with stakeholders to develop a work plan to coordinate injury prevention activity in the province.

- Research into the economic burden of unintentional injury in Saskatchewan. In response to the data released in the 2001 document, *The Economic Burden of Unintentional Injury in Saskatchewan*, a higher-level injury prevention and control strategy was drafted.

- An interdepartmental working group has been formed and is providing feedback on the strategy. Individual stakeholder consultations have been held with feedback acknowledged and incorporated into the draft document where appropriate. Additional stakeholder consultation was held in October 2003 in conjunction with the National Injury Prevention Strategy consultation. The strategy continues to be discussed with various provincial partners and will be aligned with the release of the National Injury Prevention Strategy.

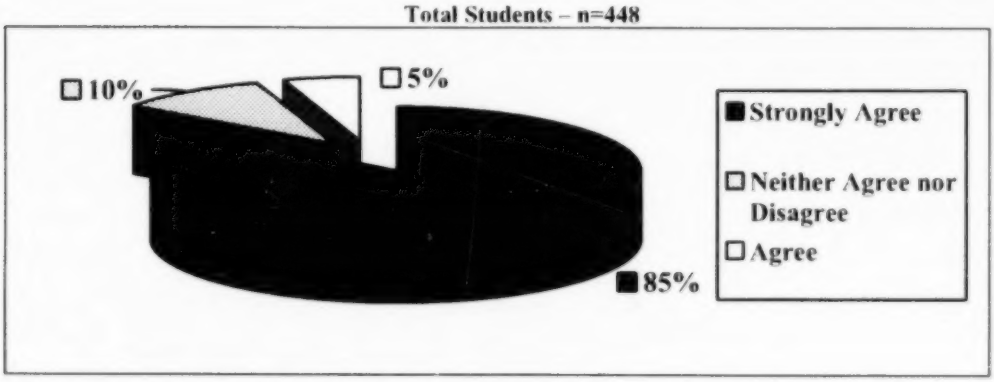
- New positions were created in 2002 to provide regional coverage and support to all areas of the province in the area of injury prevention and ABI education.

- Between December 1999 and January 2003, 33,162 individuals have participated in Brain Walk across the province. Thirty-eight percent (12,601) of participants were in the North, 27% (8,954) in the Central region and 35% (11,607) in the South.

Brain Walk Evaluations

Following each Brain Walk, students, teachers and volunteers are asked to fill out an evaluation. Figure 11 below shows that 95% of student respondents found Brain Walk information useful.

Figure 11: I will use the information I learned to keep my brain safe
For the Period April 1, 2001 to March31, 2003



One hundred percent of teacher respondents (n=30) agreed that the Brain Walk is well organized and 97% of the same sample also agreed that student awareness of preventing brain injuries has increased.

Partnerships and Increased Coordination of Services

In addition to work coordinated for the ABI Partnership project, the Provincial ABI Education and Prevention Coordinator sits on several committees that are focused on injury prevention:

- Provincial Child Passenger Safety Committee
- Saskatchewan Bicycle Safety Coalition
- Saskatchewan Safety Council – Annual Provincial Injury Prevention Symposium Planning Committee
- Senior Fall Prevention Consortium – Saskatoon, Saskatchewan
- Saskatchewan Snowmobile Safety Committee

- Brain Awareness Week Planning/Coordinating Committee
- Saskatchewan Aboriginal Injury Prevention Partnership (SAIPP)
- Growing Up with Safety Advisory Committee – Saskatchewan Labour

Addressing Special Populations

Preventing Injuries in Children and Youth
Saskatchewan Institute on Prevention of Handicaps (SIPH)

- The Saskatchewan Institute on Prevention of Handicaps works to prevent injury among children in Saskatchewan by implementing programs in the areas of bicycle safety, child passenger safety, home safety, playground safety and general injury prevention.
- Annual funding supports staffing, resource development and community support.
- Program highlights:
    - 76 people were trained in the 4-day child passenger restraint "Train the Trainer" program for 1998-2002. These trainers have, in turn, held 276 clinics during 2000-2002 in 91 communities checking a total of 6,888 car seats.
    - 20 people have been trained in Special Needs child passenger restraint training 2001.
    - 28 people have been trained as child passenger restraint technicians (2-day training) in 2001-2003.
    - coordination of the Saskatchewan Bicycle Safety Coalition and the continued efforts to secure a provincial bicycle safety legislation.

The North
- The "Train the Trainer" model has been used extensively in the North. A two-day instructor training session was held training 26 snowmobile safety instructors from the communities of La Ronge, Southend, Pinehouse, Sandy Bay, Deschambault Lake, Stony Rapids, Hall Lake, Weyakwin, Buffalo River Dene Nation, Buffalo Narrows, La Loche, Clearwater River Dene Nation, and Ile a la Crosse. In the 2000/2001 and 2001/2002 seasons, 17 snowmobile safety courses were held and certified 175 participants in their local communities.
    - Prior to this there were no Snowmobile Safety Instructors in Northern Saskatchewan and no snowmobile safety courses were held.
- ATV Safety Instructor Course (funded through the community grant program) trained 8 new instructors located in the communities of Ile a la Crosse, La Loche, Buffalo Narrows, Turnor Lake, Prince Albert, and Regina.
    - Prior to August 2001 the nearest ATV safety instructor was located in Saskatoon.
- In Partnership with the Red Cross and funded by the community grants, 11 On Board boat safety instructors from the communities of La Ronge, Ile a la Crosse, Stony Rapids, and Stanley Mission were trained in La Ronge August 2001.
    - Instructors from this training have, in turn, trained 110 people.

- Education/Prevention Program partnered with the Red Cross to host training (6 days) to develop Abuse Prevention Educators (14) across Northern Saskatchewan (funded in part by the community grant program and the Children's Action Plan).
    - To date 5 instructors have delivered education to 570 participants (mainly to students 12 years of age and older) since they completed training last summer.

"There is a lack of specific coordinated education and training for all caregivers, including professionals and families, particularly with regard to behavioural issues. Many physicians and other individuals who work with individuals with brain injuries have no specialized training in ABI."

Goal Two – Improved abilities of service providers, community, clients and their families to better cope with the impacts of their injuries.

Evaluation Question 2: Has knowledge regarding ABI and the ability to address its impact increased for individuals with ABI, their families, service providers and communities?

- Annual Brain Trust conferences (6 Brain Trusts have been held to date with a total of 904 participants). Conference participants have rated the events as valuable and informative. For example, evaluation results from Brain Trust 2001 indicated that 92% of respondents agreed to strongly agreed that the conference met their needs; 97% agreed to strongly agreed that the conference was well organized; and 88% agreed to strongly agreed that the conference provided an opportunity for networking.

- Introduction to Acquired Brain Injury course (474 total participants to date)
    - Intro to ABI 2003 Evaluation results – 82% of respondents agreed to strongly agreed that the training met their needs; 97% agreed to strongly agreed that the training was well organized; 84% agreed to strongly agreed that the material provided was useful.

- Education Days
    - There have been several education days offered to the ABI Partnership staff aimed at improving knowledge in specific areas of service delivery. Some of these education days have included legal issues, substance abuse, suicide intervention, sexuality, farm stress and program evaluation skills. Participation by partnership programs has consistently been very high for these events.

- Funding provided to Saskatchewan Brain Injury Association to provide education opportunities and resources to survivors and their families.
- *The Survival Guide: Living With Acquired Brain Injury in the Community*
    - a resource created for survivors, families and service providers
    - to date approximately 1500 manuals have been distributed

- family comments – "Yes every survivor (if they can) should read the Survival Guide and the family and friends as well"; "I cannot see how this guide could be improved – it is so helpful"
- service provider comments – "well written, easy to understand"; "I appreciate the info to caregivers – some areas are quite controversial/delicate – well done"

- Saskatchewan Health Resource Centre – ABI-specific resource section created through Partnership funds and is accessible to the public.

- Education offered by the Outreach Teams and funded projects.

- Pamphlet series – 1) Acquired Brain Injury – Partnership Project; 2) Acquired Brain Injury – Outreach Support Teams; 3) Acquired Brain Injury – Alcohol and Drugs; 4) Brain Walk; and 5) Acquired Brain Injury – Education and Prevention Services.

- Funding is available for unique or specialized education opportunities.

- Development of Mild Brain Injury resources.

- Service Provider Survey Results - Questions 5 and 6 of the service provider survey rated the Education and Prevention Component. Based on a scale of 1 to 5 with 1 representing "strongly agree" results showed:
  - "The Provincial ABI Office provided program staff with educational and training opportunities?" - **1.4**
  - "The Provincial ABI Office has developed materials required to advance education in the area of ABI?" - **1.91**

Future Direction

The following priority areas will continue to guide education and prevention activities:

- Provincial Injury Prevention and Control Strategy Development in coordination with the National Injury Prevention Strategy
- Continued Education Opportunities
- Mild Brain Injury program development
- Community Injury Coalitions/Networks will be supported
- Brain Walk evaluation refinement and program development

RECOMMENDATIONS

Based on the 196 recommendations included in the site-level evaluation reports, responses from the service provider and SGI PIR surveys, feedback from the ABI Advisory Group Evaluation Focus Day and Provincial Office staff analysis and synthesis of data, the following list of recommendations and corresponding actions will direct future program activity.

EDUCATION AND PREVENTION

The prevention of acquired brain injury and its secondary effects are major goals of the Partnership Program. Therefore, Education and Prevention activities continue to be a cornerstone of our service continuum. Many site-level recommendations spoke to the need to continue to focus attention to this service component.

Actions:

- Ensure provincial service coordination and reach of activities to remote communities;
- Continued advocacy efforts in areas of bicycle and ATV helmet legislation; and
- Implement the draft Injury Prevention and Control Strategy.

EVALUATON AND REPORTING

Improve monitoring and evaluation functions through the Acquired Brain Injury Information System (ABIIS)

Modifications to the ABIIS in 2002 meant that data elements were not required nor reported consistently across all programs. Therefore ABIIS data utilized in this evaluation phase must be qualified in many instances (e.g., Active/Inactive clients).

Actions:

- Investigate with Saskatchewan Health Corporate Information and Technology Branch (CITB) modifications to the ABIIS to track change in client status (e.g., employment, living situation, education) which are important client goals in program.

- Implement an ABIIS User Group to review data currently collected through the ABIIS. The ABIIS should be modified/improved in the future by adding and/or deleting data elements, tightening up data definitions and providing in-service/training to ABIIS Users to maintain data entry consistency.

Streamline site-level reporting requirements

The evaluation reporting requirements during this contract period required a great deal of staff training and time to complete. Further, the reporting requirements have been the same regardless of the size of program and amount of staff resources to complete the task. In order to meet ongoing evaluation/reporting requirements the Partnership should look at adopting a regular reporting format that is less labour-intensive.

Action: Adopt a new statistical quarterly reporting template to capture basic aggregate client demographics, service utilization, staffing and service flows (e.g., new referrals/waitlists, active clients, caseload sizes).

Evaluation Tools

Currently we have limited longitudinal client outcome data. Further analysis is required on current client outcome tools being utilized to determine if long-term information needs will continue to be met at both the provincial and site level.

Actions:

- Develop evaluation tool specific to children/youth
- Reconvene the Outcomes Working Group to revisit client outcomes tracking to streamline the administration protocol and further investigate questionnaire sensitivity and which tools are best administered for which client sub-populations.
- Develop standard tracking tool to measure client goal attainment.

ONGOING PROGRAM DEVELOPMENT

Continue to address program pressures/gaps

Funding/Staffing/Transportation

Site-level reports suggested enhancements in the following areas:

a. to increase overall funding to the ABI Partnership Project;
b. to address perceived staffing inequities where client caseload warrants it;
c. to address travel costs for agencies providing service to clients in rural/remote areas; and
d. to expand programming in the areas of: a) substance abuse, b) ABI-specific long-term housing/residence, and c) development of an a/vocational programming option in the North.

Action: Continue to monitor program pressures and as additional funding becomes available we will prioritize areas for future program development and/or enhancement.

Support Networks

There is a continued need for support networks for both families and individuals with ABI throughout the province. Service providers have identified the need for training to establish these support groups/networks in their local communities.

Action: encourage the formation of additional client/family support networks throughout the province.

Family

While it is encouraging to see that the goal of independent community living is being achieved, to a large degree, for the majority of our clientele, it also raises questions about the level of family burden and need for ongoing support. Our analysis of ABIIS data reveals that the number of family service events is small (and possibly underreported), therefore, it is difficult to fully ascertain the level and scope of service provided for families and gaps in service that still exist.

Action: Future activities will focus on ABIIS reporting consistency around family service events, as well as gaining other sources of family feedback (e.g., revisiting family focus group feedback and the consideration of a family questionnaire to determine caregivers' functional status) so that we can fully determine the degree to which we are meeting family needs and identify areas for future program improvements.

Residential

A gap still exists in appropriate type and supply of residential options for a small number of young ABI clients with limited supports and significant behavioural challenges.

Action: Establish a Residential Options Working Group to identify areas for action and undertake an environmental scan/needs assessment process to ascertain prevalence/need.

CONTINUE TO FOSTER INTERSECTORAL COORDINATION AND INTEGRATION

It is recognized that many sectors benefit from the services that the ABI Partnership Project provides. With that in mind, more work needs to be done both provincially and by funded programs (regional health authorities) to increase awareness within health and other sectors of the programmatic benefits that the Partnership provides to ABI clients whose cause of injury is other than an MVC.

Action: Discussion around informal and formal service and funding partnerships will continue with other sectors.

Continue to seek other funding partners
A recommendation that came out of SGI's Personal Injury Protection Plan (No Fault) Review conducted in 2000 spoke to the need for the ABI Partnership Project to seek new program funders.

Workers' Compensation Board (WCB)

Approximately 4.5% of registered ABI clients list WCB as an insurance type.

Action: A contract is being negotiated with WCB to establish a fee-for-service schedule with all three outreach teams located in Regina Qu'Appelle (Regina), Saskatoon (Saskatoon) and Prince Albert Parkland (Prince Albert) health regions. It is anticipated this contract will be in place for the 2004-2005 fiscal year.

First Nations

While First Nations people only constitute 9.4% or 96,752 of Saskatchewan's entire population (1,024,827), this group is over-represented within the ABI Partnership population at 16% or 315 clients.

The disproportionate amount of brain injuries that occur within the First Nations population (compared to overall numbers of First Nations within the general population) is an issue of particular concern in remote and northern communities. The Sask North Outreach Team reports that just under half of their clients are of aboriginal descent and that the proportion of First Nations clients has increased over the life of the Partnership to date. Many of these First Nations clients are of lower socioeconomic status and without third party insurance.

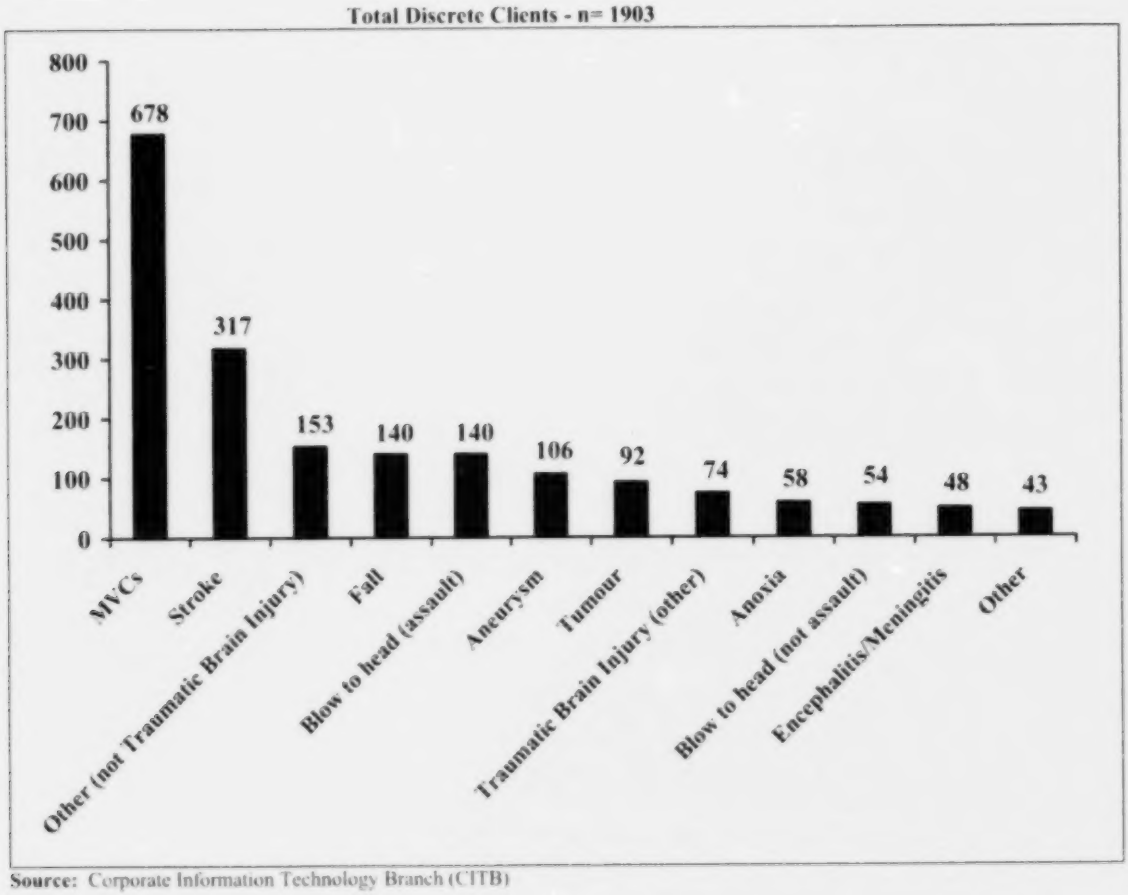
Action: Work needs to continue with First Nations communities to address the unique (i.e., language, cultural) needs of this group. Funded programs will (continue to) be encouraged to foster partnerships with First Nations communities through bands and tribal councils to ensure that the needs and service supplements of First Nations clients are being addressed. Discussions will continue to occur regarding ways to formalize these relationships.

Continue to seek program partners
Service provider feedback through survey and site-level recommendations indicates that concurrent disorders (psychiatric and substance abuse) are prevalent in the ABI population they serve. While the Partnership has arranged educational in-services to cross-train service providers working with this client group, it is apparent from this feedback that continued effort is needed to address the needs of this sub-population of ABI clients.

Action: Continue to be involved in educational events to train service providers in prevalence and treatment of concurrent disorders.

Appendix A

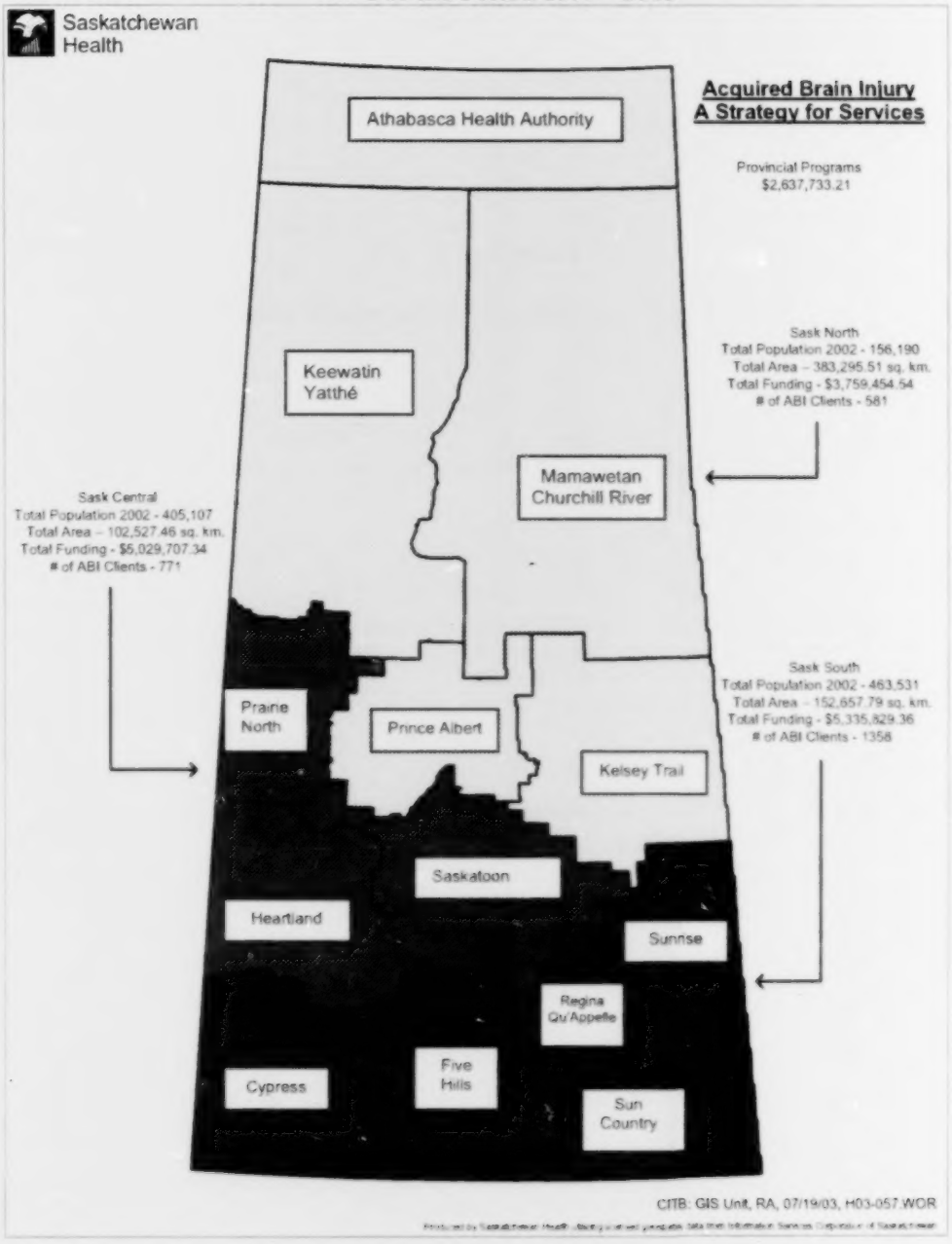
Cause of Injury
For the Period Jan 1, 2000 – March 31, 2003



Source: Corporate Information Technology Branch (CITB)

Appendix B

For the Period 1999 - 2003



Appendix C

Acquired Brain Injury Partnership Project
Service Provider Survey

Please circle the service area that applies to your program

South Central North

PART ONE

Using the gradient below as your guide, please check the number that best reflects your response.

1 Strongly Agree
2 Agree
3 Neutral
4 Disagree
5 Strongly Disagree

1. The Provincial ABI Office has provided your program with support in the area of financial management.

   1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

2. The Provincial ABI Office has assisted the Partnership Project in the coordination of services across the province.

   1. ☐ 2. ☐ 3 ☐ 4. ☐ 5. ☐

3. The Provincial ABI Office has contributed in the planning of your program's overall development.

   1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

4. Services for survivors of acquired brain injury have improved as a result of the ABI Partnership Project.

   1. ☐ 2. ☐ 3 ☐ 4. ☐ 5. ☐

5. The Provincial ABI Office has provided program staff with educational and training opportunities.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

6. The Provincial ABI Office has developed materials required to advance education in the area of ABI.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

7. The ABI Partnership Project serves the intended target population.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

8. Survivors of ABI encounter timely access to service through the ABI Partnership Project.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

9. ABI clients continue to receive valuable rehabilitation service after they leave the acute care setting.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

10. Since the inception of the ABI Partnership Project survivors of ABI report improved quality of life.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

11. The Provincial ABI Office has assisted your program in the development of a process for continued program evaluation.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

12. Communication between funded agencies within the ABI Partnership Project and the Provincial ABI Office is adequate.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

13. There are adequate information sharing and networking opportunities for funded agencies within the ABI Partnership Project.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

14. I feel like I am part of a professional network of services.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

15. Service integration and coordination for survivors of ABI has improved since the inception of the Partnership Project.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

Part Two

Please answer the following questions with respect to your personal experience working with the ABI Partnership Program.

1. Has the Provincial ABI Office been successful in addressing gaps in service through increased programming and program enhancements? Please explain.

_____

_____

_____

_____

_____

2. Do gaps still exist? Please explain.

_____

_____

_____

_____

_____

3. Please comment on the overall impact of the Partnership Project on the lives of survivors of ABI.

_____

_____

_____

_____

_____

4. Please comment on areas where program support could be enhanced.

_____

_____

_____

_____

_____

Appendix D

ABI Partnership Project
Service Provider Survey - *Qualitative Results*

Of the qualitative responses to **Question 1**, 19 of 35 respondents felt positive strides have been made in addressing gaps in services for individuals with ABI. Eleven out of 35 (31%) indicate that Partnership program enhancements are addressing gaps. Three respondents stated that the ABI Provincial Office has supported this program development and two other respondents referenced the variety of services provided through the Partnership that are meeting a variety of client needs. One respondent indicated that there is an increased understanding of ABI, another that there is increased knowledge to address ABI, and a third that there is increased quantity and access to services (i.e., those services previously only provided outside the province). Seven of 35 survey respondents provided no qualitative comments to Question 1. Nine of thirty-five respondents suggested areas for program improvements which include: three respondents commented that there is a general need for more service, one respondent commented on the need for psychology/counselling services for clients greater than 3-years post-injury (i.e., clients not accessing outreach team services); another commented on the need for service continuity (programs and standards) in all three regions of the province; one respondent indicated that there is a need for staff continuity in the provincial office to support evaluation work; another about the need for better transition between acute and community services.

In **Question 2** respondents were asked to identify if gaps still exist. Thirty-one percent of respondents (11 of 35) indicated that there is still a need to address residential options for individuals with ABI. Some spoke of particular models or particular sub-populations (e.g., young adults with ABI (especially males), individuals with severe behavioural challenges). Twenty-six percent (9 of 35) of respondents spoke to the need for program enhancements in rural areas. While 4 of 9 spoke to the need for general program enhancement, other responses focused on the need to address specific issues and/or lack of services: slow-stream rehabilitation (like SARBI), staff recruitment, two respondents spoke about the need for transportation (both that there be consideration of time allowances to travel to remote parts of rural service areas and the transportation budget to allow adequate/equitable levels of service for rural clients) another respondent spoke to the need to have transitional programming for young adults in rural areas.

5 respondents (14%) spoke to the need for prevention activities to address: language issues in the north, medium of communication (e.g., video resources), "expert" knowledge transfer to Partnership staff outside of outreach teams, and another respondent spoke of the need for strategic direction in prevention and education.

Other gaps identified (**note:** numbers in brackets denote number of respondents who identified the issue):

- (2) general service enhancements needed; (2) psychology/counselling services needed; (1) better knowledge around assessment and diagnosis of ABI; (1) better follow-up; (2) First Nations programming;
  (1) Partnership staff clarification of roles and responsibilities; (1) better intra-Partnership communication; (1) need for ABI/Substance Abuse program; (1) employment/vocational programming for the north; (4) no answer; (1) better support for spouses and lower-socio-economic clients.

Question 3 - A sample of regional survey responses speaks to the overall impact of the Partnership on the lives of ABI survivors:

- South – Have an improved quality of life, increased education and support and services close to or in their homes.
- Central – Extremely positive impact for both clients and family in a cost effective and "client driven" manner.
- North – Feedback very positive – ABI individuals/families feel they have a stronger voice.

Question 4 - Thirty-seven respondents suggested 52 areas where program support could be enhanced. Six of 37 (16%) of respondents provided no answer to this question. The most frequent theme was in the area of **program enhancement**. There were 14 responses with the main themes being: staffing (3), long-term financing (1), transportation (3), enhancements in areas of rural (2), day (1), and residential programming (3); and community support (1). The second most frequent theme was in the area of **evaluation** with 8 suggested areas for improvement: establish consistent outcome measurement tools (3), involve front-line staff in evaluative needs assessment (1), reduce quantity of evaluation reporting requirements (1), have independent evaluator (1), and contract out site-level evaluation (1), and lastly ensure evaluation addresses accountability requirements (1). Three respondents spoke of enhancements to rather than gaps in support, feeling we were meeting support needs (1), there are more services now than before (1), and that there were generally satisfied with the level of support (1). The third most frequent theme was in the area of Prevention and Education with 7 responses. Sub-themes include: consistent health sector education (2), consistent evaluation standards (1), increase amount of general public education (2), expand Brain Walk to older (youth) audience (1), conduct PET needs assessment (1)

The remaining themes are:

- Families [4] – need more support groups (1), emotional support (1), more resource materials (1), and better partnerships between family, clients and service providers (1)
- Vocational [2] - More emphasis should be placed on vocational training for competitive employment (1) and that more employment spots be procured for clients (1)
- Consistent service delivery [2]
- Consistent program standards/policies [2]
- Communication [2] with SGI (1) and between Partnership Projects (1)
- ILP [1]

- WCB [1] – pursue partnership
- Review Rural Issues [1]
- Child and Youth specific programming [1]

Appendix E

Acquired Brain Injury Partnership Project
Survey for Saskatchewan Government Insurance
Personal Injury Representatives

Part One

Using the gradient below as your guide, please check the number that best reflects your response.

1 Strongly Agree
2 Agree
3 Neutral
4 Disagree
5 Strongly Disagree

1. The relationship between SGI and the ABI Partnership Project is effective in coordinating services for clients.

   1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

2. Clients are generally satisfied with the services they receive from the ABI Partnership Project.

   1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

3. ABI Partnership Project staff is knowledgeable in the area of Acquired Brain Injury.

   1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

4. Services for survivors of acquired brain injury have improved as a result of the ABI Partnership Project.

   1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

5. The ABI Partnership Project has hosted education and training events that I have been invited to attend.

   1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

6. The ABI Partnership Project has addressed identified gaps and needs for survivors of ABI.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

7. The ABI Partnership Project serves the intended target population.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

8. Survivors of ABI encounter timely access to service through the ABI Partnership Project.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

9. ABI clients continue to receive valuable rehabilitation service after they leave the acute care setting.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

10. Since the inception of the ABI Partnership Project survivors of ABI report improved quality of life.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

11. The ABI Partnership Project has been successful in providing province-wide service to survivors of ABI.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

12. Communication between the ABI Partnership Project and SGI is adequate.

1. ☐ 2. ☐ 3. ☐ 4. ☐ 5. ☐

Appendix F

PIR Survey – *Qualitative Results*

Five SGI Personal Injury Representatives responded to the qualitative portion of the survey. Their responses are included below (note: numbers below indicate the number of respondents)

Question 1 – *New Research and information from Partnership to SGI* (n=5)
- 2 - good information (conferences)
- 1 – has attended events found not useful
- 2 - not informed of information/events.

Overall, PIR responses to this question demonstrate that there could be better communication/access to information and notification around education events.

Question 2 – *Coordination of Services between Partnership and SGI* (n=5)
- 2 - communication is good – joint involvement in client care/case management
- 2 – need better verbal and written information exchange (i.e., more lead/joint involvement would be beneficial), one SGI PIR indicated that they are often "informed after the fact" when a client requests payment for services from SGI. Another respondent indicated that there could be better and more timely access to written documentation (including supplemental medical information)
- 1 coordination works well between some staff

Question 3 - *Overall Impact of Partnership on clients* (n=5)
- 1 - very good services, nothing prior
- 1 - clients and families feel someone there to help them, don't feel alone, good education for (and appreciated by) families
- 1 – clients lives have been enriched by Partnership
- 1 – Partnership should continue as it was intended to ensure no gaps in service for ABI clients
- 1 - varied client response – some clients say they are satisfied, others feel that involvement with the Partnership is "holding them back".

Question 4 - Gaps (n=4)
- 1 – need people trained in remote areas to work on rehabilitation with ABI clients
- 1 – good transition planning and follow-up from acute care, however need for proactive follow-up by staff for a motivational clients because onus for follow-up is often left to clients
- 1 – need more school liaison/return to school support
- 1 – need care facility/group home for young people with ABI
- 1 - statistics on service provision (method, quantity) of MVC versus other cause of injury

Question 5 - Other (n=3)
- 1 - Partnership staff should obtain and utilize prior medical history for objective treatment planning

- 1 - For smoother operation need goal, role and guideline clarification
- 1 - Partnership staff should consider difference in approach based on age and sex of client

Part Two

Please answer the following questions with respect to your personal experience working with the ABI Partnership Program.

1. Do SGI Personal Injury Representatives have access to new research and information about Acquired Brain Injury through the ABI Partnership Project? Please explain.

_____

_____

_____

2. From your perspective please comment on the coordination of services between SGI Personal Injury Representatives and the ABI staff.

_____

_____

_____

3. Please comment on the overall impact of the Partnership Project on the lives of survivors of ABI.

_____

_____

_____

4. In what ways has the ABI Partnership Project addressed gaps in service? Do gaps still exist? Please explain.

_____

_____

_____

5. Other comments?

Appendix G

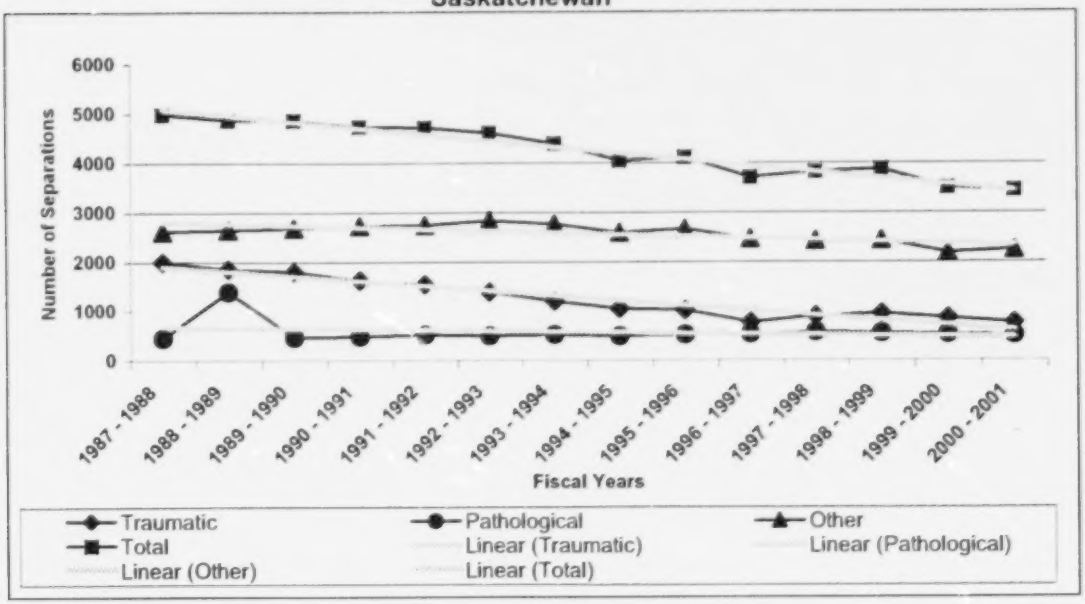
Saskatchewan Outcomes Questionnaire (SOQ)
Community Integration Sub-scale

1. **I feel like part of this community, like I belong here.**
2. **I know my way around this community.**
3. **I feel like I know the rules in this community and I can fit in with them.**
4. **I feel that I am accepted in this community.**
5. **I feel that I can be independent in this community.**
6. **I like where I'm living now.**
7. **There are people I feel close to in this community.**
8. **I know a number of people in this community well enough to say hello and have them say hello back.**
9. **There are things that I can do in this community for fun, in my free time.**
10. **I have something to do in this community during the main part of my day that is useful or productive.**

Appendix H

Reductions in ABI

Figure 1: Acquired Brain Injury Hospital Separations, 1987-88 to 2000-01, Saskatchewan



In order to analyse the trends in acquired brain injury (ABI) hospitalisations in Saskatchewan, a data run was conducted on ABI diagnostic codes used in hospital admissions over the 14-year period - 1987-1988 to 2000-2001. (Source: Corporate Information & Technology Branch, Saskatchewan Health). The ABI Provincial Office worked with the Provincial Epidemiologist, Dr. William Osei, who analysed this data and charted some interesting summary results. Dr. Osei's analysis is included in the text below.

Figure 1 above shows that ABI hospitalizations generally showed a decreased trend from 1987-88 to 2000-01. The slope was steepest in the *Traumatic* category. The *Other* category showed the mildest decline.

The risk factors for injuries occurrence are associated with the general population health determinants. The occurrence of injuries has factors associated with the individual/host, the agent (e.g., vehicle of injury) and the environment. However, the subsequent admissions to hospital or emergency rooms are also associated with the pre-existing health status, age, sex of the individual/host as well as the severity, multiplicity, site and the general impact of the injury. In addition, the availability of early intervention/response, hospital services and practice patterns of the caregivers and the institution would affect utilization of hospital services in diverse ways.

For instance, early on-site response and good emergency room services could prevent or reduce hospital stay while availability of beds, equipment, specialty and other staff or general hospital services could increase hospital utilizations.

A study of the flow of injury cases would reveal that nearly 90 percent of injuries do not get hospitalized. Of the roughly 10 percent of injuries that end up in hospital, some are self referrals, some are by Emergency Response Team, others by private clinic or general practitioners' office, or as referral from other hospitals for more specialty treatment.

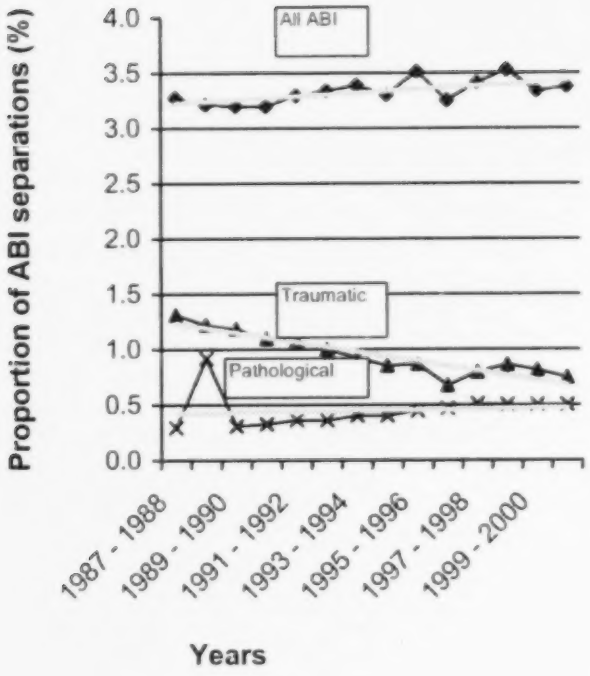
High impact injuries, such as brain injuries as well as injuries in the very young and very old individuals would tend to require hospitalizations in comparison to other injury types and age categories.

It is interesting to observe that the steepest decline in ABI injuries were the *Traumatic Injury* category. It would therefore appear that the demographics around this injury type must have changed. Without the supporting data, one might speculate that the individuals who get into the *Traumatic Injury* category may have been the healthier or younger type. It might well be that the emergency response teams and the hospital emergency rooms have more completely treated most of these traumatic type injuries without need for further hospitalization. Perhaps new treatment guidelines for injuries were developed over the study period that affected the policy on transfer of injured cases to the wards.

While the graph above charts a general decline of roughly 1,500 brain injury admissions over this 14-year period, it is difficult to answer definitely why this is the case. There has been a general decline in hospitalizations in Saskatchewan since the early 1990s due to hospital closures and hospital bed number reductions in the remaining hospitals. However, the decline in ABI admissions appears to have started before the hospital closures. It is important to keep in mind, however, that total hospitalisations demonstrate this same steadily decreasing – it is not unique to acquired brain injury.

Further analysis was conducted in order to show ABI hospital separations, as a proportion of all hospital separations (please see Figure 3). What we observe is that ABI hospitalizations maintained a steady increase in proportion to all other causes of admission. More specifically in 1987/88, ABI admissions accounted for 3.2% of all hospital admissions, increasing steadily to 3.8% by 1999/00.

Figure 2: Proportion of ABI Separations, Saskatchewan, 1987-88 to 2000-01



Note: the proportion of ABI separations is estimated as the number of ABI separations divided by the number of separations from all causes, multiplied by 100.

Given that hospital admissions for the traumatic ABI category showed a decrease over the 14 year period, and the proportion of traumatic injuries as a whole also decreased- it appears that the decrease in the number of hospital admissions for traumatic ABIs is real. Whether this is due to early intervention program success, hospital admitting policy change, or a decrease in the number of people with traumatic injury is unknown. Further analyses focusing on these issues are warranted.

REFERENCES

Acquired Brain Injury Working Group. (1995). *Acquired Brain Injury: A Strategy for Services.* (Available from ABI Partnership Program, Saskatchewan Health, 3475 Albert Street, Regina, SK S4S 6X6).

Batavia, I.E., De Jong, G., McKnew, L.B. (1991). Toward a National Personal Assistance Program: The Independent Model of Long-term Care for Persons with Disabilities. *Journal of Health Politics, Policy and Law*, 16 (3), 523-545.

Burke, D.C. (1995). Models of Brain Injury Rehabilitation. *Brain Injury*, 9 (7), 735-743.

Christoffel, T., & Gallagher, S. (1999). *Injury Prevention and Public Health: Practical Knowledge, Skills and Strategies.* Gaithersburg, MD: Aspen Publishers Inc.

Cusimano, M.D., & Mukhida,K. (2003). Acute Injuries Research in Canada. Background paper for the Canadian Institute for Health Research Listening for Direction in Injury Regional Workshops. 5.

Gamble, D., & Moore C. (2003). The Relationship between VR Services and Employment Outcomes of Individuals with Traumatic Brain Injury. *Journal of Rehabilitation*, 69 (3), 32, 35.

Gray, S.D., & Burnham, S.R. (2002). Preliminary Outcome Analysis of a Long-Term Program for Severe Acquired Brain Injury. *Archives of Physical and Medical Rehabilitation*. 18, 1447-1456.

Kolakowsky-Hayner, S.A., Miner, K., & Kreutzer, J. (2001). Long-Term Quality and Family Needs After Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation*, 16 (4), 375.

Lannoo, E., Brusselmanns,W., Van Eynde, L., Van Laere, M., & Stevens, J. (2004). Epidemiology of acquired brain injury (ABI) in adults: prevalence of long-term disabilities and the resulting needs for ongoing care in the region of Flanders, Belgium. *Brain Injury*, 18(2), 203-211.

Ponsford, J., Olver, J., Ponsford, M., & Nelms, R. (2003). Long-term adjustment of families following traumatic brain injury where comprehensive rehabilitation has been provided. *Official Research Journal of the International Brain Injury Association*, 17 (6), 465.

Whitman, Mona. (1991). Case Management in Head Injury Rehabilitation. *Rehabilitation Nursing*, 16 (1), 2-5.

Willer, B., & Corrigan, J. (1994). Whatever it Takes: a model for community-based services. *Brain Injury*, 8 (7), 648.

Smartrisk. *The Economic Burden of Unintentional Injury In Saskatchewan.* (2001).3